Religion and Ethics at the End of Life

A Qualitative Empirical Study among Elderly Jewish and Muslim Women in Antwerp (Belgium)

Goedele Baeke

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Religion and Ethics at the End of Life. A Qualitative Empirical Study among Elderly Jewish and Muslim Women in Antwerp (Belgium)

Een wetenschappelijke proeve op het gebied van de theologie (KU Leuven) en de religiewetenschappen (Radboud Universiteit Nijmegen)

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in de Godgeleerdheid
aan de Katholieke Universiteit Leuven

Ter verkrijging van de graad van doctor
in de religiewetenschappen
aan de Radboud Universiteit Nijmegen
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volgens besluit van het college van decanen
in het openbaar te verdedigen op dinsdag 13 november 2012
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te Ronse (België)

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APPENDIX: TRANSCRIPTION AND CODIFICATION OF FACE-TO-FACE INTERVIEWS 223
Summary 231
Samenvatting 239
Biography 247

BIBLIOGRAPHY

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INTRODUCTION

Jewish and Muslim attitudes toward ethical dilemmas in health care

Ethical dilemmas have always been part of human existence. Guidelines on right behaviour and good practice in everyday life have been offered by religious traditions. In the scriptures of the Abrahamic religions (Judaism, Christianity and Islam), for instance, moral exhortations emerge. The Ten Commandments found in the Hebrew Bible constitute an important basis for Jews' and Christians' moral codes of behaviour. Jews are urged to observe 613 commandments (*mitzvoth*), which concern their relationship with God on the one hand and their behaviour toward other people on the other hand. In Christianity and Islam there is no such fixed list. In the three Semitic religions, showing respect for human life is a central moral instruction. Both Talmud (*Bavli Sanhedrin* 37a) and Quran (5:32) assert that "whoever saves a soul saves all of humankind, and whoever destroys a soul destroys all of humankind". For Jews and Muslims, centuries-old exhortations are still relevant in contemporary life. Yet, taking new circumstances and developments into account, discussions on the application of religious principles today may arise. While it is clear from the Jewish and Islamic scriptures that human life has to be preserved, progress in contemporary medicine might question this fundamental religious instruction.

In Belgium, in the build-up to the euthanasia law, and ever since its enactment in 2002, debates revolved around people's right to die. Among scholars, ethicists and policy makers – most of them having either a Christian, either a non-religious humanist background – there is much discussion on the circumstances in which human beings must have the opportunity to request their lives to be ended. Until today, in societal, political, and academic conversations on the topic, voices of Jews and Muslims – the two largest religious minority groups in Belgium – are absent, while – given the multicoloured character of present-day society – there is a need for providing culture- and religion-sensitive care. Addressing this need in a sincere way presupposes having a basic knowledge of non-Christian and non-humanist views on the right-to-die discussion. This doctoral dissertation aimed to meet this lacuna by studying (Flemish) Jewish and Muslim perspectives on ethical dilemmas in end-of-life care.

Jewish and Islamic normative reflections on for instance euthanasia can quite easily be found on the Internet or in (academic or more popular) publications. Apart from taking a look at these normative instructions, we thought it was important to examine the particular ethos on the topic of a specific group of adherents of these religions. World wide, these empirical studies are very scarce. Since elderly people are more likely to appeal

to health care and to be confronted with ethical dilemmas pertaining to medical decisions, we considered it very meaningful to examine viewpoints of Jewish and Muslim women aged 55 years and more. All interviewees were living in Antwerp (Flanders, Belgium), a city housing a vast number of different religions, cultures and nationalities. This non-normative descriptive qualitative empirical study focused on two central research questions: (1) what are the attitudes of elderly Jewish and Muslim women (age $\geq$ 55) living in Antwerp (Belgium) toward ethical dilemmas which may occur in contemporary end-of-life health care?; (2) to what extent does the participants' ethos correspond with or deviate from Jewish and Muslim standpoints found in normative literature? Additionally, the study explored (3) whether there is a link between specific religious beliefs and the way ethical questions at the end of life are dealt with, and what precisely constitutes this link. Moreover, (4) regarding this link, we aimed to draw very tentative comparative conclusions with regard to two related (Abrahamic) religions (Judaism and Islam), living close to each other in the city of Antwerp (Belgium), at the same time being aware of huge differences (for instance with respect to socio-economic and educational level) between both.

Focussing on these research questions, this study is part of a larger research programme, 'Religion and Ethics at the End of Life: A Study of the Influence of Religious and Ideological Affiliation and World View on Attitudes towards End-of-Life Decisions', which was started in 2002 at the Interdisciplinary Centre for the Study of Religion and World View (Faculty of Theology and Religious Studies, KU Leuven), under supervision of prof. dr. Bert Broeckaert. In the context of this research project, two empirical studies have been undertaken. Dr. Stef Van den Branden (2006) examined the attitudes of practising elderly Moroccan men in Antwerp to treatment decisions at the end of life, and dr. Joris Gielen (2010) studied the views on this topic of palliative care nurses and physicians in Flanders (Belgium) and New Delhi (India). Set up as part of the research covenant Katholieke Universiteit Leuven-Radboud Universiteit Nijmegen, this doctoral dissertation is linked to the research expertise of prof. dr. Jean-Pierre Wils (Radboud Universiteit Nijmegen), who is connected to the Faculty of Philosophy, Theology and Religious Studies and to the Centre for Thanatology.

Grounded Theory methodology: reconstructing partitipants' way of thinking

A non-normative, descriptive, exploratory study was set up which aimed to obtain an in-depth view on elderly Jewish and Muslim women's (age $\geq$ 55) attitudes toward ethical dilemmas which may occur in contemporary end-of-life health care. Entering into and reconstructing their way of thinking via a Grounded Theory approach, we also gained an insight into the religious views of the (Jewish and Muslim) participants. As such, the study

offered us the opportunity to draw very preliminary conclusions with regard to the link between our participants' ethos and their religious beliefs. The aim of the study was *not* to develop a general theory with regard to the relationship between religion and ethics, but the empirical data of our small-scale exploratory study gave us the opportunity to come to cautious conclusions with regard to the link between religion and ethics, which may serve as a basis for future (large-scale) research. Yet, given the difficult accessibility of the studied populations (for instance, due to language barriers and the closedness of the communities) it can be doubted whether it would be conceivable to set up large-scale (quantitative) empirical studies in these populations.

The empirical data - obtained through interviews and participatory observation - served neither as an illustration for viewpoints found in normative (Jewish/Islamic) literature, nor as a test of hypotheses. A Grounded Theory methodology, which makes use of an inductive method, was applied to analyse the interview data. Grounded Theory is aimed toward a "discovery of theory from data systematically obtained from social research" (Glaser & Strauss 1967, p. 2). Thus, making use of this methodology we did not start the study "with a preconceived theory in mind", rather we allowed "the theory to emerge from the data" (Strauss & Corbin 1998, p. 12). When gathering and analysing the interview data through Grounded Theory methodology, we made use of a constant comparative method which allows to generate and interrelate categories and their properties which emerge out of the interview data. Interviewing continued until theoretical saturation was reached, i.e. until all categories were saturated (no new or relevant data emerged) (Strauss & Corbin 1998, p. 212). It is essential for generating theory that the researcher focuses on joint collection and analysis of data. In our study, after having completed an interview it was transcribed and coded as soon as possible. Through open coding, axial coding and selective coding, we attempted to make sense out of the data by systematically organizing them into a classificatory scheme, consisting of categories, their properties and dimensions. In appendix we give examples of how interview extracts were coded.

Data analysis consists of interpretation: the interviewer/researcher tries to understand the perspective of the participants by reconstructing their way of thinking through codification of the interview data. The first analysis of the interview data consists of 'open coding' (Strauss & Corbin 1998, p. 101-121): codes convey the interview content. These conceptual names or labels may emerge 'in vivo' (codes are words of the respondents themselves) or may be concepts of the analyst. Naming or labelling through open coding aims to generate a process of conceptualization or abstracting.

The code system which emerges out of this first step is still unstructured. In a second step, concepts are grouped into (more abstract) categories and subcategories. This

analytic process of relating categories to subcategories is called 'axial coding' (Strauss & Corbin 1998, p. 123-142). Additionally, in order to have a clear perception of the participants' way of thinking categories can be identified and developed in terms of their specific properties and dimensions (Strauss & Corbin 1998, p. 116-119). The principal goal of axial coding is offering depth and structure to a category by systematically developing and relating categories.

Open and axial coding of each transcript extract helped us to gradually enter into and reconstruct the way of thinking of our participants with regard to the research topics, which was the primary aim of our descriptive, exploratory empirical study. The end result of a codification process which relies on Grounded Theory is supposed to be the creation of a theoretical model, which is arrived at through 'selective coding'. Selective coding is the process of selecting and identifying a central category. Determining the (tentative) core of the phenomenon under study helps to tentatively explicate the story line of the studied phenomenon. Our small-scale exploratory study did not allow us to discover a substantial theory; via the codification process we primarily aimed at entering into and reconstructing the way of thinking of under-researched religious minorities. Nevertheless, as elaborated in the epilogue of this doctoral dissertation, we discovered some tentative core concepts, which may serve as a basis for future (large-scale) empirical studies. One tentative conclusion of the exploratory study was that image of ultimate reality or God is closely related to the way controversial moral dilemmas, such as euthanasia, in end-of-life care, are handled. Other core concepts were: autonomy (or autocentrism) versus heteronomy (or allocentrism) as determinants in dealing with contingent aspects of life, such as illness and death. Another tentative core concept was that personal experiences might influence the way one handles ethical dilemmas.

As explained, keeping the nature of our study in mind, namely being a small-scale, tentative, pioneering study among under-researched religious minorities in Belgium, we did not reach substantial theories, for instance about the religion-ethics link. As shown, the codification process resulted into tentative concepts with regard to elderly Jewish and Muslim women's way of thinking about very concrete ethical dilemmas in health care, and the possible link with their religious views. Interview analysis through codification primarily helped us to enter into and reconstruct their way of thinking. Throughout the dissertation we add excerpts from the interviews. Their aim is to exemplify the participants' way of thinking for the reader. At the same time, in the discussion part of each chapter which deals with our empirical data, we confront these interview extracts with normative Jewish and Muslim views. Doing this, we do ***not*** intend to use our data as an illustration of normative Jewish or Islamic views which are easily available in literature. Yet, we do intent to confront our reconstruction of Jewish and Muslim women's way of thinking with

normative Jewish and Muslim views and to highlight any similarities and differences between both. Nevertheless, we wanted to remain faithful to the interview data, primarily aiming at reconstructing the way of thinking of under-researched religious minorities in Belgium with regard to controversial issues, such as euthanasia.

Conceptual framework of treatment decisions in advanced disease

In order to examine ethical attitudes, it is necessary to work with clear definitions. Broeckaert & the Flemish Palliative Care Federation's (2006) pursuit of conceptual clarity with regard to treatment decisions at the end of life, such as euthanasia, led to the development of a typology, which can be found in the box below. Like in previous empirical studies of the Interdisciplinary Centre for the Study of Religion and World View (KU Leuven), in this doctoral research this conceptual framework was applied. Findings are presented regarding choices concerning (forgoing) curative and/or life-sustaining treatment (1) and euthanasia and assisted suicide (3).

(1) (Forgoing) curative and/or life-sustaining treatment

- Initiating or continuing a curative or life-sustaining treatment
- Non-treatment decision: *"withdrawing or withholding a curative or life-sustaining treatment, because in the given situation this treatment is deemed no longer meaningful or effective"*.
- Refusal of treatment: *"withdrawing or withholding a curative or life-sustaining treatment, because the patient refuses this treatment"*.

(2) Pain and symptom control

- Pain control: *"the intentional administration of analgesics and/or other drugs in dosages and combinations required to adequately relieve pain"*.
- Palliative sedation: *"the intentional administration of sedative drugs in dosages and combinations required to reduce the consciousness of a terminal patient as much as necessary to adequately relieve one or more refractory symptoms"*.

(3) Euthanasia and assisted suicide

- Voluntary euthanasia: *"the intentional administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable by the patient, at this patient's request".*
- Assisted suicide: *"intentionally assisting a person, at this person's request, to terminate his or her life".*
- Non-voluntary euthanasia: *"the intentional administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable, not at this patient's request".*

Structure of the dissertation

At the time the doctoral proposal was written, we decided which topics would be discussed in order to answer the general research questions of the dissertation. With permission of the doctoral committee of the Faculty of Theology and Religious Studies (KU Leuven), it was decided which articles would be published and clustered in the dissertation. Should we have chosen to write a traditional doctoral thesis, the same subject matters would have been treated. The chapters clustered in the dissertation were conceived as small-scale studies, suitable for individual publication in international scientific journals. As such, each chapter focuses on the central research questions, and simultaneously it has its own specific aim. Due to this clustering of articles in the dissertation, throughout its chapters, the dissertation includes repetitions, for instance of the research methodology. The dissertation constitutes of two parts (the first on Jewish, the second on Islamic end-of-life ethics), having both a brief introduction and conclusion, and it concludes with a chapter offering significant, still very tentative comparative perspectives. The fact that the Jewish part is more elaborate, has to do with the research expertise of the Interdisciplinary Centre for the Study of Religion and World View (KU Leuven). As dr. Stef Van den Branden (2006) extensively studied normative (Sunni) Islamic views on ethical dilemmas in end-of-life care, we did not assume it useful to give in our text an overview of Islamic end-of-life ethics in general. A similar study on (normative) Jewish perspectives was lacking. Therefore, we considered it necessary to discuss Jewish end-of-life ethics at greater length, including a range of chapters focussing on normative (Orthodox and liberal) Jewish views. Nonetheless, in the discussion section of the chapters which treat our empirical findings with regard to the Muslim particlpants, we also pay attention to characteristics of Islamic ethical reasoning and normative Muslim views with regard to the research topic, and, as with regard to Judaism, we explore any similarities/differences between our respondents' ethos and normative views found in the literature.

As mentioned, all dissertation's chapters are articles which are submitted for publication in international journals or volumes. With permission of the doctoral committee of the Faculty of Theology and Religious Studies (KU Leuven) the articles were collected unmodified. At the same time, the doctoral committee granted us permission to harmonize the reference system of the articles, and to make use of an author-date system. The following articles have already been published or have been accepted for publication. Chapter three was published in Mortality (Baeke, Wils & Broeckaert 2011c). Chapter four appeared in Journal of Religion and Health (Baeke, Wils & Broeckaert 2011a). Chapter six and chapter eight will be included in a volume, following on the conference 'Whoever saves a soul saves an entire world. Jewish Perspectives on End-of-Life Ethics' (Leuven, 22-24 November 2010). Chapter five was published in Nursing Ethics (Baeke, Wils & Broeckaert 2011d). Chapter seven appeared in Ethnicity & Health (Baeke, Wils & Broeckaert 2011b), chapter eleven was published in Journal of Pastoral Care & Counseling (Baeke, Wils & Broeckaert 2012b), and chapter twelve in AJOB Primary Research (Baeke, Wils & Broeckaert 2012a). (Parts of) some (other) chapters were presented at international conferences (Baeke & Broeckaert 2007a; 2007b; Baeke, Wils & Broeckaert 2007a; 2007b; 2010a; 2010b).

PART 1:

JUDAISM & ETHICAL END-OF-LIFE DILEMMAS

1 Introduction to Part 1

In this part, we examine the influence of Jewish beliefs and practices on dealing with ethical dilemmas in health care. In current bioethical debates in Western European countries, such as Belgium, we perceive the absence of Jewish voices, although Jews are an important and long-standing population in Belgium. Therefore, we considered it important to look into opinions of Jews on the topic under study. Since in the framework of the broader research programme on religion and ethics of the Interdisciplinary Centre for the Study of Religion and World View (KU Leuven), a literature review on normative (Orthodox and liberal) Jewish views on specific ethical questions at the end of life was not yet undertaken, it was included in this doctoral project. As mentioned in the introduction, all chapters were conceived as articles suitable for individual publication in international scientific journals. As a result, the dissertation includes repetititions, for instance with regard to research background and method.

In chapter two, we analyze Jewish perceptions of life and death and Jewish end-of-life rituals, on the basis of our exploratory empirical study in the Jewish community of Antwerp (Belgium) and a literature review. In this chapter, we argue that Judaism strongly rejects the rule of death, despite the fact that the Jewish tradition takes human contingency seriously. We discover that in Judaism, even when death comes knocking, stress on life prevails. The chapter focuses on three central elements which drop a hint in that direction: (1) discontinuity (life and death appear as two strictly separated spheres), (2) continuity (stress on the existence of life after death), and (3) community (which plays an essential life-giving role).

From chapter three onwards, we focus on very concrete ethical dilemmas and Jewish views on it. Chapter three discusses the (American) Jewish debate on the acceptability of using organs retrieved from brain-dead patients. In religious Jewish circles, it is disputed whether the extraction of these organs should be considered murderous. By examining this much-debated ethical query, the chapter aims to reveal the specificity of Jewish ethical reasoning, its text-centeredness and heterogeneous character.

In chapter four, Jewish perspectives on euthanasia are explored, on the basis of a review of publications of prominent rabbis who have extensively published on Jewish biomedical ethics. In the chapter, we look into Orthodox, Conservative and Reform opinions on euthanasia and we discover an inner-Jewish as well as intra-branch diversity.

Judaism teaches that life must be preserved and Jewish law recognizes that the agony of a moribund person must not be stretched. Considering this, chapter five discusses Orthodox Jewish perspectives on withholding and withdrawing life-sustaining treatment.

More specifically, we probe the position of two prominent Orthodox Jewish authorities, the late Rabbi Moshe Feinstein and Rabbi J. David Bleich, and we confront them briefly with Conservative and Reform perspectives on the topic.

Apart from reviewing normative Jewish perspectives on treatment decisions at the end-of-life, we considered it important to explore the attitudes of a particular group of Jews with regard to these issues. We entered into and reconstructed their specific way of thinking through codification of face-to-face interviews. Chapter six, seven and eight focus on the findings of our descriptive, exploratory qualitative empirical study in the Jewish community of Antwerp and help us to answer our research questions, (1) what are the attitudes of elderly Jewish women (age $\geq$ 60) living in Antwerp (Belgium) toward ethical dilemmas which may occur in contemporary end-of-life health care; (2) to what extent does the participants' ethos correspond with or deviate from Jewish standpoints found in normative literature, and (3) whether there is an interplay between specific religious Jewish beliefs and the way ethical questions at the end of life are dealt with, and which facets of religiosity play a major role. Chapter six deals with Jewish perspectives on medicine and illness: we outline the perceptions of our research participants and frame these with Jewish theological convictions and present-day rabbinical views on medicine and illness.

Chapter seven presents results of our empirical study with regard to active termination of life. The views of our research participants are presented and discussed, keeping the central research questions of the dissertation in mind. Chapter eight discusses the opinions of our research sample with regard to withholding and withdrawing life-sustainment. Again, the participants' way of thinking is confronted with normative Jewish views and the interplay between the interviewees' religion and world view is tentatively addressed.

This doctoral project set up a descriptive, exploratory qualitative empirical study in the Orthodox Jewish community of Antwerp. Most Belgian Jews (approximately 40.000-50.000) live in Brussels and Antwerp. Smaller populations are found in Gent, Oostende, Liège, Charleroi, Arlon and Waterloo. We opted for Antwerp as our research setting, given the very specific religious character of its Jewish community. In contrast to Brussels, which houses mainly liberal and non-religious Jews, the Antwerp Jewish community claims to be fundamentally Orthodox. While Jews in Brussels are spread over the city, the Antwerp Jewish community lives very concentrated in the neighbourhood of the Central Railway Station, the diamond quarter and the city park. In this area, a lot of facilities (synagogues, prayer houses, ritual bathhouses, Jewish schools, kosher shops and restaurants, etcetera) can be found to help Jews in their Orthodox way of life.

Jews in Antwerp are member of an Orthodox Jewish community: Shomre Hadas, Machsike Hadas, or the small Portuguese-Israelite community. Moreover, a significant

group of Hasidic Jews, associated with diverse Hasidic branches, set their stamp on Antwerp. Throughout history, the Antwerp Jewish community was gradually attributed a stricter Orthodox character. Gutwirth (2004) and Vanden Daelen (2008) refer to the migration wave of Eastern European Jews at the end of the nineteenth century, and to the rising amount of Hasidic families and their increasing visibility in Antwerp in the post-war period. Today, next to Jerusalem and New York, Antwerp is recognized as an important centre of Hasidism. The intense community life found in the Antwerp Jewish community reinforces social control, which strengthens its Orthodox character.

In our study, fieldwork and exploratory talks in the community showed that Jews in Antwerp are 'united in diversity'. Despite its Orthodoxy, the Antwerp Jewish community proofs to have a varied membership. Our qualitative empirical study wanted to capture this diversity. Therefore, snowball sampling was done among three different 'groups' of Jews: (a) Hasidic Jews, (b) non-Hasidic Orthodox Jews, and (c) secularized Orthodox Jews. About one quarter of the Antwerp Jewish population is Hasidic, about 40% is non-Hasidic Orthodox, and about 35% is secularized Orthodox. In contrast to the Hasidic and non-Hasidic Orthodox Jews, secularized Orthodox Jews in Antwerp renounce religious Judaism. They might be (hesitatingly) religious, but they do not consider themselves Orthodox, in the sense that they do not or only partially follow Jewish law. Nevertheless, they consider themselves as member of the Orthodox Jewish community of Antwerp, on which they rely for Jewish education, kosher food (some secularized Orthodox Jews follow this prescription out of habit/tradition), and rites of passage (such as circumcision, marriage, burial). This group underlines its Jewish identity, but does not interpret it in religious, but rather in ethnic and cultural terms.

In the (strict) Orthodox Antwerp Jewish community, contact between men and women is restricted. Taking this into account and considering the sensitive research topic, we supposed that gaining access to ***male*** (Orthodox) Jews and inspiring confidence in them would be difficult for a ***female*** interviewer. Therefore, only Jewish ***women*** were interviewed. As elderly people are more likely to appeal to health care and to be confronted with ethical dilemmas related to it, the interview sample included Jewish women aged 60 or more. Given its (strict) Orthodox character, the Antwerp Jewish community is rather closed, which sometimes complicated gaining access to it and recruiting participants. Additionally, we experienced that the target group was very busy with managing their family and with commitments (for instance, charity initiatives) in the Jewish community. Evidently, on and before Jewish holidays, interviews could not be done. Additional factors which made recruitment of participants difficult were the sensitivity of the research theme and the women's concern to express "the correct Jewish view". A lot of women who were asked to participate, perceived themselves as unsuitable for an interview, because of their limited

knowledge of Judaism. Several times, the researcher was advised to contact an expert of Judaism. Despite these difficulties, the researcher gained access to the community and 23 Jewish women, between 60 and 75 years old, consented to participate in the study. Apart from interviewing, the researcher paid attention to participatory observation (several synagogue ceremonies were attended). Research data were gathered between June 2008 and January 2009. All interviews were done in Dutch. The interviewer had no knowledge of Yiddish, and a basic knowledge of Modern Hebrew (Ivrit). She completed a language course of Ivrit (level 1) at the Institute of Jewish Studies in Antwerp. In the table below, we give an overview of the research participants. We mention their name (pseudonym), native country, age, their (family's) migration year to Belgium, number of children (Child), knowledge of languages (Lang) [(m) stands for 'mother tongue', (l) stands for 'little knowledge'], their religious self-definition (SD), and the Jewish community they belong to.

(a) Hasidic interviewees

Name	Native country	Age	Migration Belgium	Child	Lang	Religous SD	Community
Chanah	France	64	before World War II	0	Yiddish (m) Dutch French English German Hebrew	"Orthodox", "Hasidic" (Klausenburg-Sanz)	Machsike Hadas
Nechama	Belgium	60	after World War II	5	Yiddish (m) Dutch French English Spanish Czech Russian Polish	"Orthodox", "Hasidic" (Satmar)	Machsike Hadas
Chaya	Belgium	60	before World War II	5	Yiddish (m) Dutch French Hebrew German English	"Orthodox but not strict" "Hasidic" (Gur)	Machsike Hadas
Devorah	Israel	72	after World War II	4	Hebrew (m) Yiddish	"Strict Orthodox" "Hasidic"	Machsike Hadas

					Dutch French English	(Gur)	
Leyla	Belgium	60	after World War II	8	Yiddish (m) Italian English French Dutch	"Ultra-Orthodox" "Hasidic" (Belz)	Machsike Hadas
Suzannah	Israel	73	1963	5	Dutch (m) French Hebrew English Yiddish German	"Orthodox" "Hasidic" (Lubavitch)	Machsike Hadas Shomre Hadas
(b) Non-Has	**dic Orthodox**	**interviewees**					
Tzippa	Switzerland	61	1972	4	German (m) Dutch French English Hebrew Yiddish Italian (l)	"Orthodox"	Machsike Hadas
Elizabeth	The Netherlands	70	after World War II	4	Dutch (m) English French German Yiddish Indonesian	"Orthodox"	Machsike Hadas
Sarah	Indonesia	62	1957 (father before World War II)	10	English (m) French Dutch Hebrew Yiddish	"Ultra-Orthodox"	Machsike Hadas
Tamar	Switzerland	73	1957	2	German (m) Dutch Yiddish English Hebrew Italian French	"Orthodox"	Machsike Hadas
Miriam	Belgium	74	before World War II	4	Dutch (m) French (m) Yiddish Hebrew (l) German (l)	"Ultra-Orthodox"	Shomre Hadas

					English (l)		
Esther	Belgium	60	before World War II	3	French (m), Dutch English Yiddish Hebrew German (l)	"Modern Orthodox"	Shomre Hadas
Norah	Uzbekistan	63	after World War II	3	Polish (m) Yiddish (m) French Dutch English Hebrew Italian German (l)	"Modern Orthodox"	Shomre Hadas Machsike Hadas
Judith	Belgium	60	after World War II	3	Yiddish (m) Dutch French English Hebrew Polish (l)	"Orthodox"	Shomre Hadas
Danielle	Belgium	60	before World War II.	5	French (m) Dutch Hebrew English Yiddish	"Strict Orthodox"	Machsike Hadas
(c) Secularized Orthodox interviewees							
Dianne	Belgium	60	1946	2	Yiddish (m) French Dutch Hebrew English Portuguese Spanish Italian German	"non-religious" "more liberal" "conservative"	Shomre Hadas
Dianne	Belgium	60	1946	2	Yiddish (m) French Dutch Hebrew English Portuguese Spanish	"non-religious" "more liberal" "conservative"	Shomre Hadas

					Italian German		
Joanna	Belgium	69	1932	2	Dutch (m) French English German Italian Yiddish Hebrew	"non-religious but member of the Orthodox Jewish community"	Machsike Hadas
Ruth	The Netherlands	68	1952	2	Dutch (m) French English German (l)	"non-religious"	Shomre Hadas
Leah	Switzerland	63	before World War II	2	Dutch (m) French English Hebrew Yiddish (l)	"religious"	Shomre Hadas
Nicole	Belgium	75	before World War I	1	Dutch (m) French (m) Yiddish	"non-religious" "liberal, but not Reform"	Shomre Hadas
Lisa	Belgium	70	1936	4	French (m) Dutch English German Yiddish (l) Hebrew (l)	"Conservative, in the sense of following the Jewish tradition"	Shomre Hadas
Arielle	Belgium	61	before World War I	2	English (m) Dutch French	"hesitatingly religious" "member of the Orthodox Jewish community" "secularized"	Shomre Hadas Portuguese community
Josephine	Belgium	62	before World War II	2	French (m) Dutch German Yiddish English Italian (l) Hebrew (l)	"deeply religious" "not Orthodox" "liberal"	Shomre Hadas Machsike Hadass

2 Jewish Coping with Death: Expression of Life

2.1 Introduction: Judaism, religion of life

Life is an essential part of the Jewish religious tradition, even where death is very near. According to us, three aspects – which come forward when reviewing Jewish attitudes toward and praxis at the end of life – drop a hint in that direction. Jews see a strict separation between life and death. As a matter of fact, the Jewish tradition underlines an explicit *discontinuity* between life and death. Death, being an unclean realm, has to be kept distant from life, a realm which is essentially clean and pure. Second, despite this stress on discontinuity, Jewish eschatology lays down faith in a life after death (*continuity*). Again, life dominates death, in other words, continues after death. Third, the huge significance of life according to Jews is also clearly noticeable when considering the role of the *community* at the end of life. Jews clearly acknowledge that being interrelated is part of their shaped condition. In other words, in the same way as God has shaped human beings to be interrelated alive, the community bears the responsibility to keep each individual Jew alive, especially when his/her life is threatened, in case of poverty, illness and death.

This article ensues from a literature review, as well as a qualitative empirical study, conducted in Antwerp (Belgium), on Jewish illness and death perceptions and end-of-life ethics. First, it aims at exploring to which extent the importance of life, and the elements of discontinuity, continuity and community in this respect, come forward in conversations with individual Jews (in Antwerp, Belgium) about the end of life, thereby paying attention to Orthodox and non-Orthodox views. Second, the article explores how these elements are reflected in Jewish practice of end-of-life rituals – which we come across in literature and during participant observation and interviews in the Jewish community of Antwerp – and how this mirrors Judaism's emphasis on life, while reviewing these rituals chronologically (but not exhaustively).

2.2 Life and death perceptions among Jews in Antwerp (Belgium)

2.2.1 Antwerp Jewry: a short introduction

Today approximately 40.000-50.000 Jews live in Belgium (Abicht 2006; Vanden Daelen 2008), mainly spread over two large communities: Brussels and Antwerp. In contrast to the larger community in Brussels, which chiefly houses liberal (religious and non-religious) Jews, Antwerp Jewry is essentially Orthodox (Abicht 2006), as the estimated

15.000-20.000 Jews in Antwerp are member of an Orthodox Jewish community (Machsike Hadas, Shomre Hadas or the rather small Portuguese community). Moreover, a significant group of Hasidic Jews – associated with diverse Hasidic sects (Gutwirth 2004; Robberechts 1990, pp. 270-275) – set their stamp on Antwerp.

The essential Orthodox character which is ascribed to the community may not stifle its diversity. To date, no exact data exist on the Jewish population in Antwerp (and Belgium), only estimated numbers can be indicated. About 25% of Antwerp Jewry is Hasidic (Gutwirth 2004), about 40% is non-Hasidic Orthodox and about 35% is secularized Orthodox. Whereas for Orthodox (Hasidic and non-Hasidic) Jews being Jewish means following God's commandments, articulated in Jewish law, secularized Orthodox Jews understand their Jewish identity in ethnic and cultural terms. For them being Jewish essentially means that they belong to the Jewish people and strive for its continuation by passing on Jewish tradition and culture. They do not consider themselves Orthodox, yet they say to belong to the Orthodox Jewish community, which provides them facilities for Jewish rites of passage, for instance religious burial, which act for them as important Jewish identity markers. At the same time, they distinguish themselves explicitly from progressive Jewish denominations, for instance the Reform community in Brussels, because, according to them, they carry innovations in Judaism too far.

2.2.2 Methods

Given the female sex of the researcher and the strict separation between men and women in traditional Judaism, only women were included in the study. Snowball sampling was applied among elderly (age ≥60) Hasidic, non-Hasidic and secularized Orthodox Jewish women in Antwerp. Face-to-face interviews were done in the interviewees' home, following Grounded Theory methodology (Glaser & Strauss 1967; Strauss & Corbin 1998), making use of a semistructured topic list on religion, illness, death and end-of-life decisions. In order to gain insight into the participants' religious and ideological convictions and practices, a set of questions was developed for which we relied on the multidimensional religiosity measurement model of sociologists Glock and Stark (1966). They distinguish five "core dimensions of religiosity" (Glock & Stark 1966, pp. 19-20) – ideological, intellectual, ritualistic, experiential and consequential – and we added a social dimension of religiosity. For each of these categories we formulated a number of questions. Data collection continued until theoretical saturation was reached, i.e. when no new elements and insights came forward from further interviewing. After the interviews had been conducted, they were transcribed verbatim and anonymized making use of pseudonyms. The Grounded Theory methodology was used to code and analyze the

interview data. By adding codes to the data and through constant comparison, key concepts were identified in the interviews and categories were systematically generated and interrelated. For the data analysis MAXQDA 2007 was used.

2.2.3 Results

2.2.3.1 Participants' demographic characteristics and religious identity

The 23 interviewees were aged between 60 and 75 years, with a mean of 65 years. (The ancestors of) 12 respondents lived in Belgium before the Second World War and 11 respondents migrated to Belgium afterwards. Participants were born in Belgium (n=13), the Netherlands (n=2), Switzerland (n=3), Indonesia (n=1), Uzbekistan (n=1), France (n=1) and Israel (n=2). The overwhelming majority of the respondents were multilingual, mastering a total of between three and nine languages. Seventeen of them were married, 3 were divorced and 3 were widow. Orthodox (Hasidic and non-Hasidic) respondents had noticeably larger families (0-10 children) than secularized Orthodox Jewish respondents (1-4 children). All Orthodox participants lived in the neighborhood of Antwerp's Central Railway Station and the diamond quarter, in contrast to the majority of the secularized Orthodox respondents. Fifteen participants were Orthodox (6 Hasidic and 9 non-Hasidic) and 8 interviewees were secularized Orthodox. Huge differences in religious identity were found between secularized Orthodox and Orthodox Jewish women. While the majority of the secularized Orthodox Jewish respondents reported to be non-religious or indecisively religious, every Orthodox woman interviewed called herself religious or very religious.

2.2.3.2 Participants' perceptions of life and death

2.2.3.2.1 Discontinuity

All participants, whether Hasidic, non-Hasidic Orthodox or secularized Orthodox, recognized the inescapable finality of life. Growing older and dying were considered part of life.

> Everyone has to die. There is no single human being who stays alive. It's like that. Moses too had to die. He wanted to enter the Promised Land, and yet, he had to die. (…) Everyone has to die. (Hasidic woman)

Despite this realism toward death among all interviewees, the way in which they dealt with the mortality of human beings differed. Whereas most Orthodox, both Hasidic and non-Hasidic, participants stressed the ultimate importance and sanctity of human life,

secularized Orthodox interviewees disputed its absolute sacred nature. Indeed, the former did not consider life as the possession of human beings, but they perceived it as a precious gift from God, which is only on loan to human beings, who are summoned to take utmost care of it. In contrast with this view, for the latter, human beings own their lives and bodies, and therefore have absolute autonomy over it. Indeed, most of the secularized Orthodox interviewees did not express to have faith in an ultimate reality or God who determines everything.

> We know that we are not the boss and the body is not mine. (Hasidic woman)

> Why can you make decisions during your whole life, for sixty, seventy years, 24/24, and then you should not take the most important decision in life? (...) You only have one life, and I think, you can have a say in it, in your own life. (secularized Orthodox woman)

Having faith in the God-given nature of human beings the Orthodox participants showed an enormous respect for human life, even at the very doorstep of death. Whereas secularized Orthodox participants were more inclined to withhold and withdraw life-sustaining treatment and to accept active termination of life in case of a terminally ill patient, the overwhelming majority of the Orthodox, both Hasidic and non-Hasidic participants, stressed the importance of the preservation of life. For them, every moment of life, regardless of its quality, must be cherished, because, in their opinion, being alive gives human beings the opportunity to serve God by following his commandments.

> For a Jew every day is important, each hour, each minute, each moment he can do something God asks us to do. So, every moment of life is important. And he has to do everything to live. (Hasidic woman)

As most Orthodox, Hasidic and non-Hasidic, interviewees believed that God is the ultimate owner of human life, only God determines when the hour of death sets in. While Orthodox Jews expressed the view that death, as much as life, is God-given and thus meaningful, secularized Orthodox participants considered death as a natural, inescapable fact, a (cruel) destiny for every living organism. Orthodox interviewees, both Hasidic and non-Hasidic did not deny the harsh reality of the mortality of human beings, but for them death, as much as life, is utmost sacred. They reported that God's decision to take away human life should be bestowed respect.

> It's very sacred, death, and the dead is also watched over, he cannot be left alone until he's buried. The burial, it's very important that it happens fast,

> because it's a difficult time, the dead is not here and not there. So, it's very important that death is bestowed respect. (non-Hasidic Orthodox woman)

As is clear from this quotation respect for the reality of death is shown through the performance of appropriate end-of-life rituals, for instance a speedy burial. Remarkably, although death was not spiritualized in the way Orthodox interviewees do, all secularized Orthodox women who participated in our study were absolute proponents of Jewish burial. Despite their unbelief or hesitating faith in God and though they did not dwell on the sacred character of death they strongly expressed the wish to be buried according to Jewish rituals and in a Jewish burial place. Given their membership of one of Antwerp's Orthodox communities, they indicated that they can appeal to the service of the *chevra kadisha*, the Jewish burial society.

2.2.3.2.2 Community

The secularized Orthodox participants' wish to be buried in a Jewish cemetery, is linked to the importance they attributed to community bonds. As already mentioned, these interviewees did not understand their Jewishness in religious, but in ethnic and cultural terms. Throughout the interviews the respondents' pride of belonging to the Jewish people came forward and they stressed that their (ethnic) Jewish identity should be remembered after death. In this way, the cohesion of and integration in the Jewish community continues after life.

> It's a way to stay part of a people. I say it, the Jewish people is something special. You have a religion, but there is an origin as well. (...) And I believe this keeps on living, for always. (...) It's a feeling of togetherness. (...) It's something that makes me feel Jewish. That's me, that's part of me. (secularized Orthodox woman)

The worldwide Jewish community is indeed famous for its cohesion, and the Orthodox participants in our study as well stressed the intensity of Jewish solidarity and togetherness in good as well as in bad times. In times of ultimate need, when life is in danger, for instance when touched by illness or death, the connectedness and solidarity among Jews wherever they dwell is very strong.

2.2.3.2.3 Continuity

Orthodox participants' reasons for stressing the importance of a Jewish burial extended much further than the motives of the secularized Orthodox interviewees. This is comprehensible against the backdrop of secularized Orthodox participants' understanding of death as the final destination for human beings. According to them death is the ultimate end of life and Jews' togetherness constitutes the only reason for being buried at a Jewish cemetery. They considered having faith in a hereafter as irrational and illogical.

> No, I don't think so that we, all the dead, one day will rise from the grave. Where will they all go? It's beautiful to hear that everyone will be okay and that Messiah will come, and that the dead will rise, but the world is not so big. Where will all those people, from hundreds and hundreds of years, go? When you think logically, that's difficult. Isn't it? When you're a believer, than you believe everything, then you don't think logically. A believer is not rational. (...) According to me a believer is very strong, but absolutely not logical. (secularized Orthodox woman)

On the other hand, Hasidic and non-Hasidic Orthodox interviewees, reported that the destination of human beings surpasses death. In fact, they believe that earthly life is only a preparation for the hereafter: human beings will rise from the grave – which clarifies their wish for eternal burial at a Jewish cemetery – and they will be judged and rewarded according to their deeds on earth.

> Our life here is a preparation for the hereafter. And if we behaved well, then it will be very good in the hereafter. If not, you will endure hardship. (Hasidic woman)

> According to our religion, we have to think of death, every day. Why? Because we have to do everything, we live with the idea of a hereafter. So, we want to arrive at the little station on the other side. And for this we have to follow certain laws, and perform our duties. (...) Every day we have to live as if we are ready to reach the other world. (...) This is the purpose of our life. (non-Hasidic Orthodox woman)

2.3 JEWISH END-OF-LIFE RITUALS' EMPHASIS ON LIFE

2.3.1 Sanctifying the moment of death

As shown, unlike our secularized Orthodox respondents, the Hasidic and non-Hasidic Orthodox interviewees stressed the huge importance and sanctity of human life.

They considered life to be very precious, as it displays divine sparkles in us. Even at the very doorstep of death every second of life is considered valuable. Indeed, according to Jewish law a *goses*, a moribund person, has to be treated as a living person (Zlotnick 1966 p. 31). The moment of dying may not be quickened, nor may it be delayed (Jakobovits 1975 p. 123). In this respect, when caring for a *goses* the strict separation between life and death comes forward. Even when a person is in the throes of death, it is forbidden to make preparations for burial and bereavement rituals. Emphasizing the discontinuity between life and death at this point does not mean that the impending death is denied. As soon as it is clear that death is imminent, the family of the dying person is informed.

At this point, the community aspect, the importance of which was felt strongly in our fieldwork, comes to the fore. "Hours of intensive gathering" (Martel 2004, p. 23) and joint prayer follow. If possible and desirable the *goses* is urged to say the *vidui*, the confession of guilt. To prevent the *goses* to be needlessly worried upon the citation of the *vidui*, he/she is told: "Most of those who confessed did not die, and many who did not confess died. Many who are walking the streets recite the confession, and in reward for confession you will live" (Heilman 2001, 15). The *vidui* makes mention of an almighty God who controls healing as well as death, a profound Jewish conviction, very present among our Orthodox interviewees as well. A Hasidic interviewee said: "we never have the right to judge who may live and who not, that's always heavenly work". The community aspect at this stage of Jewish end-of-life rituals also comes forward when the *goses* is encouraged to reconcile with fellow beings with whom he/she lives in discord. He/she is called to repentance (*teshuva*) and summoned to restore his/her relationship with God and with his/her neighbor. Only in this way he/she will have a place in the world to come (*olam ha-ba*).

During the last moments of life the *Shema Yisrael* is repeatedly prayed. Recitation of this prayer when death is imminent is a final expression of the *goses'* Jewish identity. Thereupon, he/she can die in peace. According to Heilman (2001, p. 16) as well as Rabbi Goldstein (2006, p. 54) the transition from life to death has a deep religious meaning and is most sacred. The physical imminence of death reminds human beings of their dependence on God. At the same time, human beings are not completely powerless when facing death. By framing the end of life with rituals (singing psalms, reciting prayers) the community has the opportunity to sanctify and hallow this moment.

On the one hand these rituals express that death is taken very seriously. The clean and pure realm of life – which is even manifest in the process of dying as the moribund is considered a living person – can be abruptly interrupted. In this discontinuation of life the unclean realm of death enters, which fills the community with awe. Indeed, in our study the Orthodox interviewees stressed that as much as life is sacred, death must be shown utmost

respect as well. On the other hand the denial that death has the final word comes forward. By repenting before death and by reciting the *Shema Yisrael* and other prayers and psalms, the moribund and the community stress their faith in a God, who guarantees the continuity of life after death. In sincerely addressing the reality of death, on the one hand, and denying the triumph of death, on the other hand, the community plays an essential role.

2.3.2 Respect for the deceased

2.3.2.1 The prohibition to celebrate life

This ambiguity – taking death seriously and defeating death – also comes to the fore when considering the funeral rituals. The moment of death turns the deceased's relatives into *onenim*, mourners[1]. During this period of grieve, *aninut*, the bereaved are confronted with the contingency of human existence. By exempting the *onenim* from a few positive commandments, *mitzvoth*, they can pay attention to the deceased. Moreover, the *onenim* are urged to refrain from celebrating life, by forgoing a few religious obligations (cf. Zlotnick 1966, p. 72) such as praying, saying blessings (*berakhot*), wearing *tefilin* and studying Torah. They are also summoned to refrain from sexual intercourse, work, eating meat, drinking wine, shaving and cutting hair and bathing (Zlotnick 1966, pp. 48-51; Goldstein 2006, pp. 78-79; Lamm 2000, pp. 26-29; Martel 2004, p. 49). In this way they show solidarity with the deceased, who is no longer capable of performing these things (Martel 2004, p. 49): "Do not celebrate life in the face of the dead" (Heilman 2001, p. 27). Moreover, confronted with (the unclean sphere of) death, which is in a way the summit of alienation from God, who is fundamentally associated with the pure and holy realm of life, the desperate relative cannot adequately sanctify life and fulfill his relation with God (Martel 2004, pp. 57-60).

Showing profound respect for the deceased was repeatedly underlined by our interviewees. This implies, among others, arranging a speedy burial. Indeed, keeping the body, shaped in the image of God, among the living, while the soul has already ascended to God, is utmost irreverent (Lamm 2000, p. 22). Heilman (2001, p. 26) stresses that an extended period of *aninut* would furthermore be harmful and disorienting for the surviving relatives. An excessive focus on this phase of sorrow and grieve, during which one is taken over by the sphere of death, bears the risk of being completely cut off from the sphere of life.

Respect for the deceased is a constantly returning element in the rituals performed immediately after the moment of death. The corpse is covered while pronouncing a benediction, in which God is praised as the Righteous One. At this moment of affliction,

the relatives hold on to God's righteousness. It is customary to open the windows at the moment of death to facilitate the soul to escape and ascend. A candle is put at the head side of the deceased, light being the symbol of life and the eternal living soul. Where it is customary stagnant waters are poured out[2] and mirrors are covered up[3].

As stressed by our interviewees, from the moment of death on until burial the deceased is not left alone. A guardian (***shomer***) vigils over the body while reading from the book of psalms. This watching over the deceased does not take the form of a comforting social gathering around the corpse. This would betray the deceased. Respect for the deceased is essential during the period of ***aninut***. Thus, 'looking at' the deceased is completely un-Jewish. This would not be "a fair farewell" (Martel 2004, p. 61): the dead person is no longer animated, he is powerless and he cannot react and determine who is allowed to watch him and who is not. According to Rabbi Lamm (2000, p. 33) observing the mortal remains is also contradictory from another point of view: whereas Jewish rituals and prayers that surround passing away and burial confirm death as a reality, watching the dead person could lead to a persistent denial of death and could prevent an adequate coping with bereavement.

Respect for the deceased also entails that the surviving relatives may not be comforted before burial. Only when the corpse is buried, marking a definite farewell, one goes back to the sphere of the living, the realm of comfort and sorrow. The tearing of clothes (***keriah***) by the close relatives, also shows respect for the deceased. The ***keriah*** is "the most noticeable expression of grief in Judaism" (Evers 1998, 179). Traditionally this tearing of clothes was done immediately after death, but today it is often, as is the case for Antwerp Jews, performed directly before burial with assistance of the ***chevra kadisha***, the Jewish funeral society. *Keriah* symbolizes the torn heart of the surviving relatives. Tearing the clothes according to a ritual prescribed in Jewish law expresses the "inner conflict" (Martel 2004, p. 50) of the surviving relative in a controlled, prescribed and disciplined way (Wolowelsky 1996, p. 471). Showing grieve in a controlled, symbolic way is also a sign of respect for the deceased.

2.3.2.2 The community's life-giving role: creating order out of chaos

At the end of life the bonds between the living (and between the living and the dead) are strengthened. At this moment of utmost doubt and alienation the life-giving aspect of communality comes to the fore. The Jewish community does not only play an important role during the bereavement period, also during the period of ***aninut***, during which it takes care of the dead person, together with his/her family.

> In effect, both for the bereaved and for all the rest of the living, these first moments after death and before the funeral define a time whose essence is to test the strength of the ties among those who survive, demonstrating in a dramatic and often unforgettable way who must be there for the dead and for the bereaved in extremis. Thus, from the earliest moments after death, the often invisible strands that link the dead and the living in a net of obligations and emotions begin to appear (Heilman 2001, p. 30).

The crucial role of the community from the moment of death was a key element in our conversations with members of an Antwerp *chevra kadisha*, literally 'holy fellowship'. This Jewish funeral society takes the lead in providing an honorable burial. The *chevra kadisha* consists of a group of volunteers who prepare the (body for) burial. Since respectfully treating and burying the dead is seen as an act of supreme sanctity, this is the task of devout, religious Jews who live according to *halacha* (Jewish law) and who are strongly integrated in the Jewish religious community. The tasks of the *chevra kadisha* are the last gratuitous favors one can do to a deceased. The members of the holy fellowship perform a *tahara*, ritual washing, put on the shrouds (*tachrichin*) and lay the mortal remains in a coffin. Even though the corpse is no longer animated, the mortal remains must be treated with utmost respect. After all, the body is a gift from God and, consequently, is extremely sacred, a conviction which was repeatedly emphasized in our interviews. The *chevra kadisha* accomplishes this *mitzvah* (commandment) by purifying the body and by preparing it for burial.

The performance of *tahara* by the *chevra kadisha* not only expresses the crucial role of the Jewish community, also continuity of life and separation between life and death come forward in this ritual. *Tahara* is performed in order to sanctify the body, in which the soul was present during life time. Indeed, the body is a gift from God that has to be returned to the Creator in a pure state, awaiting the day of judgment. In this respect *tahara* is the last emphasize of the intimate connection between God and human being. *Tahara* is essentially a purifying and sanctifying process. According to Heilman (2001, p. 41) the ritual washing is the beginning of the process of repair and restoration, and compensates for the disorder and confusion caused by death. *Tahara* creates order in the chaos, gives structure and meaning. That which is essentially unclean, the mortal remains, because of the corrupting character of death and decay, is purified. In this way, the human struggle against death and human helplessness at the moment of death is symbolized, and the most profane and unclean – death – becomes the most holy.

Heilman (2001, 41) refers to the fact that *tahara* has a paradoxical character. On the one hand, death cannot be denied by performing *tahara*. On the contrary, when performing the ritual washing, death is in front of human being's eyes. On the other hand, performing

this ritual confirms the continuity of life. Thus, *tahara* is a transition ritual that unites the contradictory Jewish notions of death: the mortality and the decay of the human body and the faith in the world to come and resurrection. *Tahara* is "an expression of collective confidence that even for the lifeless body, death is not final" (Heilman 2001, 41). So, the body is not only prepared for burial, it is also prepared for resurrection and return to its Godly source (Heilman 2001, 41). The shrouds, *tachrichin*, too are evidence of Jewish faith in the hereafter. These are simple, white, linen or cotton shrouds on which no zips or buttons are found. The corpse is clothed making use of temporary knots, that deny the definitive character of death[4].

Tahara creates order and life, shapes the transition from death to life, from the stain of death to a pure return to God. Indeed, according to Torah a corpse is in the highest degree of uncleanness, since it can no longer sanctify life by performing God's commandments. The *chevra kadisha* performs the process of sanctification for the deceased, as a result of which he/she can return to God in a pure state. *Tahara* discloses the paradox of the status of the deceased in the Jewish tradition: on the one hand the corpse is considered to be unclean, on the other hand it must be treated with utmost respect. The uncleanness of the body preserves it from being treated without respect (Martel 2004, pp. 80-81) The unclean mortal remains inspire awe in human beings.

Accompanying the coffin to the cemetery is a *mitzvah* for every Jew, since each individual Jew is fundamentally embedded in the Jewish community. In our fieldwork, it appeared that it is not customary for, especially Orthodox, Jewish women in Antwerp to accompany the corpse to the grave. Two essential parts of the ceremony before burial are the *hesped* and the *Kaddish*. The eulogy or *hesped* praises the good deeds and character of the deceased. According to Martel it has an emotional and intellectual function (Martel 2004, p. 109). The *hesped* stimulates emotions among the relatives and makes the community conscious of the loss it suffers as a result of the death of a community member. Thereupon community bonds are confirmed and strengthened. For Heilman (2001, p. 91) this eulogy also serves as a moral lesson for relatives in order to inspire them in their way of life. Surrounded by the community the deceased is brought to his/her final resting-place, where the *Kaddish* is prayed. This *Kaddish* expresses the continuity of life after death. It expresses the hope for new life after death: when Messiah comes there will be a new creation, God's temple will be restored in Jerusalem and the dead will rise from the grave (Neusner 1991, p. 149). The Jewish faith in life after death is one reason to oppose cremation (Evers 1998, pp. 180, 230). On the contrary, in Reform Judaism cremation occurs (Cohn-Sherbok 2004, pp. 275, 279). Since everlasting burial rights cannot be guaranteed in Belgium and taking Jewish faith in a hereafter into account, which requires eternal burial, Antwerp (Orthodox) Jews bury their dead on Jewish cemeteries in the Netherlands. Moreover, even secularized

Orthodox interviewees felt aversion towards cremation and expressed the wish to be buried surrounded by other Jews.

Burial produces order out of chaos, in the same way as *tahara* does (Heilman 2001, p. 74). Burial is a transition ritual that brings about the passage of the dead person to the sphere of the dead and the return of the living to the sphere of life. Evidently, burial confronts the community with the reality of death (discontinuity), but at the same time life is constantly publicly confirmed (continuity), by reciting prayers and psalms which express trust in God, praise His righteousness and put trust in new life. Burial gives expression to the faith that death is the end of earthly acting, but not of living. As accompanying the dead to the cemetery is an utmost important *mitzvah* for every Jew, the burial also endorses the mourners' bond with the community and reaffirms the communal bonds after being confronted with death: "the mortality of one person does not presage or guarantee the death and disintegration of all" (Heilman 2001, p. 74)

In the Jewish customs and rituals meant to pay respect to the deceased, the central aspects of discontinuity, continuity and community are found. Discontinuity comes forward in the mourners' attention for the deceased and their impossibility to celebrate life and in the fundamental confrontation with mortality and decay at the moment of *tahara* – ritual washing – and burial. Simultaneously, in *tahara* and burial the continuation of life after death is stressed. Both rituals create order and life (purity) out of chaos and death (impurity). In this transition, from discontinuity to continuity, the community plays a crucial role, by taking up the obligations of ritual purification and accompanying the deceased to the cemetery, in this way expressing solidarity and maintenance of communal (life-giving) attachment.

2.3.3 Respect for the living

The last rituals at the graveyard symbolize the transition from *aninut* (grieve) to *avelut* (mourning). The integration of the mourners in the community comes forward. The words of the *Kaddish* are the first publicly spoken words of the mourners. By reciting the *Kaddish* they join generations of mourning Jews. After this, the mourners pass a row of comforting community members, who are reciting words of condolence. According to Rabbi Evers (2005, p. 36) this is the first step of reintegration in the community. In the same way, Fishbane (1989) characterizes Jewish mourning rites as a process of resoclalization. Upon leaving the cemetery, in some Jewish communities it is customary to throw some earth and/or grass backwards over the shoulder. The backwards throwing of earth would symbolize human mortality – discontinuity; grabbing grass and throwing it away would symbolize new life and resurrection – continuity (Heilman 2001, 116; .Martel

2004, 117). Before leaving the burial place, hands are washed. It symbolizes purification after contact with death and "marks the boundary between life and death" (Martel 2004, p. 118). After all, immediately after burial the period of *avelut* (mourning) sets in.

2.3.3.1 Mourning: gradual return to life

The Jewish tradition has three mourning periods: a seven-day (*shivah*) and thirty-day period of mourning (*sheloshim*) – which both start on the day of burial, and a twelve-months mourning period – starting on the day of decease – for children who lost a parent. *Shivah* is an intensive, seven-day mourning period, consisting of three 'days of weeping' and a four-day period of lamentation. In Antwerp, *shivah* is usually sat by Orthodox as well as secularized Orthodox Jews. For *shivah* commandments and prohibitions are formulated for the mourners and the community. These do's and don'ts help the mourners to focus intensively on the deceased, to contemplate, to come to terms with their sorrow and to return gradually to everyday life. "If tahara prepares the corpse for the journey of death, shivah prepares the mourners for the return to life" (Heilman 2001, p. 123). With regard to this reintegration in everyday life, the community plays a central role. Its essential responsibility and the importance of being embedded in the community was several times stressed by our interviewees, both Orthodox and secularized Orthodox, and clearly noticed in our fieldwork in Antwerp. By postulating prescriptions for the community, the *halacha* overrules the presupposition that mourning is a private matter (Evers 2005, p. 16). On the contrary, rituals during *avelut* give expression to the communal character of mourning. This is among others reflected in the meal of condolence traditionally offered to the mourners by the community members in the house where *shivah* is sat, usually the house of the deceased. The meal of condolence consists of bagels and hard boiled eggs, which symbolize the cyclical nature of life, and is eaten in silence while sitting on low *shivah* chairs. During *shivah* the mourners sit nearly on the ground, as expression of a low self-esteem and of loneliness and the loss of the beloved who is just now buried in the earth. Offering a meal of condolence expresses comfort, but also wants to stimulate the next of kin to resume the thread of life.

The task of the community is not limited to offering this meal of condolence, they also have to fulfill the *mitzvah* to comfort the mourners. "It is a man's duty to imitate God: as God comforts the bereaved, so men must do likewise" (Lamm 2000, 132). The community members have to visit the bereaved during the mourning period at least once. The presence of the community prevents loneliness and an isolated coping with grieve – "congregation is the Jewish antidote to death's abandonment" (Heilman 2001, 130) – and offers structure and order for the mourners and for the community. Though, the Jewish

tradition takes human barriers to comfort into account: words often are not adequate to express profound comfort. Therefore the Jewish tradition stipulates that comfort is above all offered by silent presence. Indeed, the Jewish tradition forbids the comforter to address the mourner before he/she is spoken to. The mourner decides when he/she wants to be comforted and when he/she wants to spend some time alone. Customary words of comfort are: "May the Almighty comfort you among the mourners of Zion and Jerusalem".

Moreover, it is the community's responsibility to provide a *minyan* in the house of mourners three times a day for prayer and recitation of *Kaddish*. This prayer has to be recited while standing, traditionally by the male mourners in a *minyan*. In Antwerp, this *minyan* cannot always be guaranteed, in case the house of the deceased is situated outside the Jewish quarter – which is situated around the Antwerp Central Station, the diamond quarter and the city park – where most Orthodox, both Hasidic and non-Hasidic, Jews live. For parents *Kaddish* must be recited during eleven months, for other deceased family members (son, daughter, brother, sister, spouse) during thirty days. Contrary to the burial *Kaddish*, this mourners' *Kaddish* (*avelim*) does not make mention of death but is essentially a laudation of God, Creator of life. Reciting *Kaddish* is "a sign of their [the mourners] having made their peace with the Almighty and with the reality of death" (Heilman 2001, p. 131). It is an expression of the acceptation of the human lack to overcome death, but at the same time it gives praise to God who "stands for life" (Martel 2004, p. 259), and it expresses the human trust and faith in God, who triumphs over death and creates peace among the people on earth. This content of *Kaddish*, together with the fact that *Kaddish* – because of the holiness of the prayer – can only be prayed in community (in *minyan*), reveals its comforting function. Moreover, praying *Kaddish* in *minyan* has a connecting power (Martel 2004, p. 261) and strengthens community bonds in this time of despair, disorder and estrangement.

Apart from this healing and connecting power, Jews believe that *Kaddish* has a beneficial effect on the deceased. From the Middle Ages on it was stressed that one ought to pray for the salvation of the deceased's soul. After death, the soul goes to *Gehenna*, where it is purified during twelve months, at the most, before being allowed to enter paradise, *Gan Eden*. Reciting *Kaddish* helps the soul to ascend to heaven. According to the Jewish tradition a son has to recite *Kaddish* for his deceased parent during eleven months – and not during twelve months out of respect for the deceased: "Pausing a month early indicates our confidence that the person's life was sufficiently meritorious to have avoided the full twelve months of cleansing" (Goldstein 2006, p. 162).

During *aninut* it is forbidden for the mourners to celebrate life (Heilman 2001, p. 170). This is also the case during *shivah*. Explanations for this prohibition to experience the joys of life are: concentration on the deceased, expressing feelings of guilt towards the

deceased and not arousing his/her jealousy – he/she is no longer capable of celebrating life. These prohibitions stimulate the mourners to abstain from luxury and pleasure and to set themselves apart. Direct contact with death causes alienation and harms the surviving relatives' personality and identity. The mourners' life is incomplete, as their relationship with God is "shocked" (Evers 2005, pp. 45-46). Not cutting and shaving hair, not bathing, not wearing leather shoes during *shivah* indicate "wanting to be without status, wanting to distance oneself" (Martel 2004, 268; Lamm 2000, p. 67; Evers 2005, p. 45). Wearing the same outer garment, showing the *keriah* tear made after death, during whole *shivah* points to the "mood of the mourner" (Martel 2004, p. 138).

The prohibition to have intercourse indicates abstaining from pleasure and multiplication and clearly marks the phase of alienation of life in which one finds oneself. Likewise, the mourner does not want to take care of livelihood and engage in festivities. As study of Torah is associated with delight, it is in principle also forbidden during *shivah*. Moreover, it is forbidden for the mourner to leave the house where *shivah* is sat during the first three days of *shivah*. On Sabbath the mourner is allowed to go to the synagogue, where he/she does not take his/her usual seat to emphasize that his/her life has taken a radical turn (Martel 2004, p. 268). This is also customary during *sheloshim*, the second (thirty-day) mourning period. Since Sabbath is a celebration of the whole community and since being accepted by the whole community has a comforting effect, it is not allowed to publicly comfort the mourners and mourn on Sabbath. Obviously, private, inner mourning is not suspended.

On the seventh day, one hour after morning prayer, the mourners rise from *shivah*. "On this day they are greeted with the life-affirming and resurrecting charge 'Arise'" (Heilman 2001, p. 153). The end of *shivah* means repair of order: "the dead go their own way, and the living go back to life" (Heilman 2001, p. 154; De Vries 1968, p. 287). In some Jewish communities, in Antwerp particularly among Hasidic and non-Hasidic Orthodox Jews, it is customary to make a short walk as an indication of this reintegration in and return to the community (Martel 2004, p. 155; Lamm 2000, p. 140; Fishbane 1989, p. 77).

After seven days of mourning a less intensive period of mourning – *sheloshim* – begins. *Sheloshim* counts thirty days, starting from the day of burial[5], and carries with it the prohibition of cutting nails, cutting or shaving hair, attending festivities, taking one's usual seat in the synagogue, marriage, wearing clothes that are new or washed with soap (Zlotnick p. 69; Lamm 2000, p. 141; Martel 2004, pp. 162-163). One is allowed to have a wash, but it is forbidden to take a luxurious bath or shower. *Keriah* clothes may be taken off. Thus the end of shivah does not mean the end of mourning. By introducing several phases of mourning the Jewish tradition affirms that recognizing and accepting death and eventually cutting oneself off the sphere of death, is a gradual process. Little by little,

through the different phases of mourning, the mourner is offered less structure and more freedom. In this way the next of kin can return to and reintegrate into the sphere of the living (Heilman 2001, pp. 158-159) slowly but surely, and continue their relationship with the community. For Martel (2004, p. xxviii) elements of separation, gradualness and continuity are essentially part of the mourning process. During *sheloshim* as well the *Kaddish* is recited in *minyan* several times a day during prayer service. On the thirtieth day, after the morning prayer, *sheloshim* is broken.

For children who have lost a parent, the breaking of *sheloshim* is not the end of mourning. From the moment of the parent's death, children are supposed to mourn during one year. Stressing the unique and irreplaceable parent-child relationship, the Jewish tradition asks to honor one's father and mother, even after death: "The child must honor the parent in life and after death" (*Bavli Qiddushin* 31b). As this special parent-child relationship goes beyond death, detaching oneself from the sphere of death and continuing life within the sphere of the living takes more time (Heilman 2001, p 183; Martel 2004, p. 167). After breaking *sheloshim* not all prohibitions are cancelled out. In principle, it is still forbidden to cut/shave, to wear new clothes, to attend festivities, to take one's usual seat in the synagogue (Martel 2004, pp. 168-170).

The parent's children are supposed to recite *Kaddish* daily for an eleven-months period. As stated earlier, reciting *Kaddish* has a connecting function. This prayer nourishes the belief in continuity between the living and the dead, on the one hand, and with the sphere of life on the other hand. Moreover, as mentioned, saying *Kaddish* is beneficial for the deceased's soul, who is under God's judgment during one year, at the most. Although the mourning period for grieving children lasts twelve months, according to Jewish tradition *Kaddish* must only be recited during eleven months, out of respect for the deceased. By reducing the period of *Kaddish* recitation from twelve to eleven months, the child pays honor to the deceased parent. In this way trust is shown in the fundamental goodness of the parent, whose soul is not to be cleansed during one whole year. Discontinuing *Kaddish* prematurely also guarantees the good public reputation of the deceased (Heilman 2001, p. 186; Lamm 2000, p. 154). On the last day of this year of lament the graveside is visited and the grave stone is set. When the last day has passed, mourning ceases. According to Jewish tradition it is not desirable to mourn and comfort longer than is laid down in tradition.

> Whosever sees a mourner within thirty days should comfort him and then ask him how he is feeling. After thirty days, but within twelve months, he should ask how he is feeling and then comfort him. After twelve months, he may in no sense remind him of his mourning (Zlotnick 1966, p. 87).

After all, "consolations that go on past their time do not ease the return to life; they impede it" (Heilman 2001, p. 194). Indeed, the Bible teaches us: "There is a time to weep and a time to laugh; a time to mourn and a time to dance" (*Ecclesiastes* 3:4).

2.3.3.2 Yahrzeit & Yizkor: affirmation and celebration of life.

On *yahrzeit* the death of the beloved one is remembered. On the first *yahrzeit* the year of grieve has come to an end and the soul is supposed to be cleansed in *Gehenna* and allowed to enter *Gan Eden* (Evers 1998, p. 225): "For the full twelve months after death, the body still endures, and the soul goes up and goes down. After twelve months, the body is null, and the soul goes up but doesn't go down again" (*Bavli Shabbat* 152b-153b). Every year, on *yahrzeit*, the *Kaddish* is recited so that the soul ascends increasingly in *Gan Eden*. A candle is lit which symbolizes the soul and new life, for the soul of the deceased as well as for the next of kin (Heilman 2001, p. 196). Among Orthodox Jews in Antwerp it is customary to offer refreshments and a toast on life (*le-Chajim*) after the synagogue service. Especially Hasidim do not regard *yahrzeit* as a day of grieve and fast, but of joy (Ribner 1998a, p. 177; Ribner 1998b, p.218), a day on which the soul's ascent and life are celebrated (Heilman 2001, p.199).

Among Antwerp Jews it is customary to set the grave stone on the first *yahrzeit*. In principle this can also be done after *shivah* or *sheloshim*. Setting a stone is a *mitzvah* in the Jewish tradition and goes back to *Genesis* 35:19-20, where is told that Jakob puts up a grave stone for Rachel. Initially, the grave stone was only a marking and only had a practical function. Gradually the symbolic meaning took over: stones are forever and summon the surviving relatives to remember the dead forever (Martel 2004, pp. 173-174). They function as a "physical remembrance" (Evers 1998, p. 219). Instead of bringing flowers to the burial place, Jews put a pebble stone on the grave, a practice which is clearly noticeable at the Antwerp Jewish communities' cemeteries in Putte (the Netherlands). Putting down a (little) stone probably comes from the old custom to heighten the grave upon each visit to protect it against vandalism. Even though the Jewish tradition advises against frequent visits of the graveyard, considering the tradition's monotheism[6] and its concern for the surviving relatives not to stick to the sphere of death, the number of stones on the grave can be a memorial, a sign that "the deceased still lives on among the living" (Martel 2004, p. 178).

Four times a year *Yizkor* is prayed in the synagogue in memory of the deceased. In this prayer the community asks God to remember the souls of the deceased, whose names are mentioned in the prayer. Those members of the community who have not lost their parents, leave the synagogue when *Yizkor* is prayed. The prayer expresses the bond between the members of the Jewish community: "my dead and all Jewish dead, my loved

one and the patriarchs and matriarchs of all of us" (Heilman 2001, p. 218). It also contains a promise of charity (*tsedaka*). These inner-worldly actions honour the dead and bring about, in the same way as *Kaddish*, merit for the deceased's soul in the hereafter[7]. Heilman (2001, p. 222) emphasizes that *Yizkor* is not only a commemoration of the dead, but also chiefly an affirmation of life. Although *Yizkor* does not make mention of resurrection, it does affirm the living relationship between the deceased and the surviving relatives.

The mourning periods, which set in after burial, symbolize a gradual transition from discontinuity to continuity. Being confronted with the death of a beloved one, relatives are alienated from life and cut off from the community. With the community members' (essential) help, the mourners gradually regain trust in (new) life and become reintegrated in the community. Elements of discontinuity in this last phase – leading to reintegration in life – diminish little by little: although still externalizing their alienated and shocked condition, the prohibition for mourners to celebrate life gradually weakens. Slowly but surely, attention shifts from the (sphere of the) dead to the (sphere of the) living. In this sense on *yahrzeit*, which concludes the year of grieve, life is celebrated: the earthly life of the invincible community and the afterlife of the deceased. Indeed, Judaism does not regard death as the end of life, but as a transition, a profound conviction which was found among the Hasidic and non-Hasidic Orthodox interviewees of our study. Without denying the inevitability of death, Judaism is essentially a life-affirming religion.

2.4 Conclusion: life prevails

From the findings of our empirical study as well as from a review of traditional Jewish end-of-life rituals, it appears that three central aspects mirror the traditional Jewish emphasis on life: the essential role of the *community*, the *discontinuity* – strict separation – between life and death and the *continuity* of life after death. Our analysis has shown that the Jewish community plays a crucial role in assuring life. Even our secularized Orthodox interviewees emphasized the essential cohesion of Jews (worldwide). Each individual Jew is embedded in a community, which assures the continuity that is threatened by poverty, illness and death.

For the secularized Orthodox respondents, this continuity of life after death was only perceived on the level of remembrance: burial on a Jewish cemetery not only affirms one's Jewish identity, it also guarantees an everlasting, tangible remembrance of the deceased (and his/her Jewishness). For traditional Orthodox Jews, this continuity has a larger scope and a deeper religious meaning, and is situated both on the level of the living and the dead. Religious Jews – the *chevra kadisha* – purify the dead (*tahara*), so that they can return to their Creator in a clean state and make the transition to *olam ha-ba*. As transitional

rite it affirms the continuity of life. Also the recitation of *Kaddish* recognizes this. On the level of the living this continuity finds expression in mourning periods and rituals, which alleviate the loneliness of the relatives, and which ensure the gradual reincorporation of the mourners in the community. Jewish end-of-life rituals reflect Jews' denial that death is the definitive end. Not only the knots (instead of the buttons) on the shrouds, also the burial *Kaddish* and the ban on cremation express the hope and the trust in new life after death.

In the same way, our Orthodox, both Hasidic and non-Hasidic, interviewees reported that life prevails. When discussing and thinking about death they did not lose sight of life, which they considered of utmost importance. Even at the very doorstep of death, life predominates. Every second of life must be preserved and cherished, and when earthly life comes to an end, new life is expected. To assure that appropriate respect is paid to life and death, an important task rests on the shoulders of the Jewish community. As is made clear, not all members of the Antwerp Orthodox Jewish community share this stress on the predominance of life. Although being embedded in the community and expressing the wish to stay integrated in it after death, by having a Jewish burial, secularized Orthodox Jews in our study said not to have faith in the triumph of life after death. For them death is the definitive end of life.

And yet, for the Hasidic and non-Hasidic Orthodox participants in our study, when death sets in, it has to be respected as God's will. Even though the Jewish tradition is forward-looking – casting a look at the future world to come – Jews also are aware of the discontinuity between life and death. Jewish tradition makes a strict separation between life and death. The living and the dead ask for a specific treatment. The equivalent of death is uncleanness, the equivalent of life is purity. Only after the deceased has been shown respect – by performing religious rituals like *tahara* and burial – the sphere of the living is addressed. The recognition of human mortality and the inevitability of death point in the direction of discontinuity. Nevertheless, the realism towards earthly death goes hand in hand with faith in the continuity of life. As much as death is certain, life will continue. In the words of Heilman:

> The aftermath of death is new life, not just for the dead [...], but also for the living. Even as it seems at first to tear at the fabric of society and life, death enables people who are touched by it to realize how connected they are to life and to others among the living, and how even dying cannot breach the bonds between the living and the dead (2001, p. 232).

[1] According to *halacha* seven relatives become *onen*: father, mother, brother, sister, son, daughter, spouse. Judaism makes a clear distinction between mourners before the burial (*onenim*) and mourners after the burial (*avelim*). Following Jewish law, during *aninut* (grieve) mourners may not be comforted, as in this period the last

honours must be paid to the deceased. After burial the attention shifts to the living. At this point the period of *avelut* (mourning) sets in.

[2] According to the tradition the angel of death dips his poisonous sword in all stagnant waters found in the deceased's home. See *Bavli Abodah Zarah* 20b. (see Martel 2004, p. 9). Moreover, water is poured as a sign for the community that a death has occurred (see Lamm 2000, p.4).

[3] This custom is interpreted in different ways: 1) relatives should only be concerned about the deceased and his/her speedy burial; 2) mirrors can cause vanity and sexual desire; 3) relatives ought not to be confronted with their confusion and despair; 4) one could catch the face of the dead in the mirror; 5) it is not appropriate to mirror the divine image of man, as the Divine itself is affected by the death of one of his creatures (see Martel 2004, p. 55; Lamm 2000, pp. 99-100).

[4] In Reform Judaism practice may differ (Cohn-Sherbok 2004, p. 279).

[5] In this sense, the first (seven-day) period of mourning, *shivah*, is part of the thirty-day period *sheloshim*.

[6] Excessively visiting the graveyard could result in having faith in mediators between God and the individual Jew. This would be in conflict with the Jewish faith in God's unity (Lamm 2000, p. 193).

[7] In Judaism poverty is seen as a kind of death. Giving charity is giving life.

3 American Jewish Approaches to Contemporary Ethical Issues in Medicine: The Case of Organ Retrieval from Brain-Dead Donors

3.1 Introduction

Worldwide, a great number of people are on a transplant waiting list. Several of them will die if a suitable donor is not found in time. Even though the need for organs is a universal problem, the ways in which the ethical dimensions are addressed differ widely. It is quite plausible that religious people might not deal with it in the same way as, for instance, non-religious humanists do. Differences might relate to a different world view; indeed, world views, conceptions of God, humankind and life – in other words, the way everything *is* – influence opinions on what *ought* to be, including what to decide in the face of an ethical dilemma (Baeke, Wils & Broeckaert 2011b; Gielen, Van den Branden & Broeckaert 2009a). The aim of this article is to expound on the specific character of Jewish ethical decision-making by presenting a succinct overview of Jewish viewpoints and arguments on death determination and organ transplantation. Specifically, as most organs are retrieved from brain-dead donors, we investigate whether, from a religious Jewish perspective, retrieval of organs from heart-beating bodies is considered acceptable. For this we focus on the rich American Jewish literature, written from both a religious Orthodox and a religious liberal (Conservative and Reform) perspective. On the Orthodox side of the spectrum, we discuss the contemporary debate between prominent Orthodox rabbis in the United States based on the diverging views of Rabbi David Bleich and the late Rabbi Moshe Feinstein and his son-in-law Rabbi Moshe David Tendler. On the liberal side of the spectrum, we highlight the opinions of the Conservative Rabbinical Assembly's Committee on Jewish Law and Standards and of the Reform Central Conference of American Rabbis. We focus on ethical debates within American Jewry, and do not include the recent public debate and the law on brain death and organ donation in Israel (Jotkowitz 2008a; Jotkowitz & Glick 2009b; Lavee *et al.* 2010).

Apart from indicating divergences and similarities in Jewish opinion, we pay attention to the underlying rationale and ask if similarities and differences on the discussed issue between rabbis and branches can be traced back to their specific ways of handling Jewish tradition – its textual and legal sources. Further, are there denominational specificities in dealing with contemporary ethical issues and/or can we speak of a trans-denominational Jewish ethical decision-making process? When trying to answer these questions, we take a non-normative religious studies and comparative religious ethics perspective. As non-Jewish researchers, interested in the way ethical reasoning functions in

different religions, we are neither willing nor able to formulate a normative standpoint on the issue at hand.

3.2 Determination of death

Being very positive towards medicine, urging human beings to seek recovery (Isaacs 1998, pp. 28, 32; Rosner 1999, pp. 99–100), and stressing the utmost preciousness of human life (Bleich 1993; 2010; Rosner 1986, p. 35), the Jewish religious tradition most probably takes a positive stance on organ donation. Nevertheless, among rabbis the ethics of this issue is thoroughly debated. A central element in their discussion is the question of the determination of death. Indeed, saving someone's life should not be at the cost of the donor's life. In other words, the very concern is whether a donor is definitely dead at the moment at which his/her organs are removed.

Judaism traditionally is a law-based religion. In virtually all aspects of life the corpus of Jewish law (*halacha*) is involved. The *halachic* (legal) corpus of texts is central to debates on contemporary (ethical) issues (Newman 1992) such as the determination of death. The primary source which is cited in the *halachic* discussion on the definition of death is a passage in tractate *Yoma* of the Babylonian Talmud. This Talmudic fragment deals with the question of whether or not Sabbath can be violated in order to save human beings who lie buried under the rubble of a collapsed building:

> One must remove debris to save a life on the Sabbath, and the more eager one is, the more praiseworthy is one. [. . .] Not only must one remove the debris in the case of doubt as to whether he is there or not, as long as one knows that he is alive if he is there; but, even though it be doubtful whether he is alive or not, he must be freed from the debris. [. . .]. If one finds him alive, one should remove the debris. But that is self-evident if one finds him alive? – No, the statement is necessary for the case he has only a short while to live. And if he be dead, one should leave him there. *(The Talmud, Bavli Yoma 84b, 85a)*

From the passage it appears that it is allowed and even mandatory to undertake a rescue operation on Sabbath, even if it is uncertain that any victims are still alive. Thereupon the question is asked how far the rescuers must search, in other words how they know whether a person is alive or dead:

> How far does one search? Until [one reaches] his nose. Some say: Up to his heart. [. . .] R. Papa said: The dispute arises only as to from below upwards,

> but if from above downwards, one had searched up to the nose, one need not search any further, as it is said: 'In whose nostrils was the breath of life'. *(The Talmud, Bavli Yoma 84b, 85a)*

The problem of defining death arises at the moment any victims are found (Sinclair 2003, p. 228); Jewish law prohibits moving mortal remains on Sabbath. In the cited source, two divergent voices are distinguished. The majority view runs as follows: it is the presence of respiration which signals that the person is still alive. Proponents of this position refer to *Genesis* 7:22, "all in whose nostrils was the breath of life", as a Biblical basis. Thus, according to this view, a person has to be examined up to his/her nose. Conversely, in the minority opinion it is the victim's heart, rather than nose, which has to be examined. Contrary to the majority opinion then, the absence of a heartbeat is sufficient proof of death (Herring 1989, pp. 46–47). However, it was the majority opinion that was adopted by the major *halachic* codes (Nevins 2004): "virtually all of the major codifiers, starting with Maimonides, accepted the first view as law – i.e., it is the nose which indicates life or death by the presence or absence of detectable breathing" (Herring 1989, p. 47; Sinclair 2003, p. 229).

Despite this apparent consensus on the sign of death, the determination of death has been widely debated over the centuries of Jewish history (this Talmudic tractate in particular and the Talmud in general already reveal the very discussion culture of Jews). After all, establishing the moment of death with extreme precision is most essential in *halacha* with regard to purity laws, laws of inheritance, providing a speedy burial, care for dying people, and so on. Moreover, growing technological advances in medical care (the possibility of artificial respiration, organ transplantation, brain death) increased the pressure on the *halachic* definition of death. Against this background, Jewish rabbis and *posekim* (specialists of Jewish law) still search for an acceptable, empirical detectable criterion of death: in Jewish religious perspective this is the moment when the soul leaves the body.

3.3 Brain-dead donors and organ transplantation

Jewish debate on death determination became complicated with the formulation of brain death criteria in a report issued in 1968 by the Ad Hoc Committee of the Harvard Medical School, which paved the way for organ transplantation using organs retrieved from heart-beating brain-dead donors (Campbell & Sutherland 1999; Machado 2005; Zeiler *et al.* 2008). This was a milestone in Western medicine, as initially organs were only retrieved from patients after cardio-respiratory arrest. Although currently most organs for transplantation are retrieved from brain-dead donors, to meet the huge demand for organs non-heart-beating donation is also considered as an option (Vincent & Brimioulle 2009;

Devey & Wigmore 2009). In Judaism there is an important debate about the acceptability of organ transplantation, on the one hand, and the use of brain-dead donors, on the other.

3.3.1 Desecration or a noble act?

From a Jewish perspective, the debate on organ donation and transplantation reveals some *halachic* commands and prohibitions which, at first sight, seem to be in direct contradiction to this contemporary medical possibility. The discussion is situated on two levels: the level of living and that of post-mortem organ donation and transplantation. As this article's specific focus is organ retrieval from brain-dead donors, only the latter discussion will be sketched.

On the level of post-mortem organ transplantation, the Jewish tradition stresses the priority of the *mitzvah* (commandment) to save human life over all other considerations, except for the ban on the three cardinal sins (murder, idolatry and forbidden sexual relations). However, the *halachic* commandment to respect the deceased (*kevod hamet*) implies that (1) mortal remains may not be mutilated, as this is desecration; (2) one is not allowed to derive benefit from the dead; and (3) a deceased person has to be buried as fast as possible and in its entirety (Rosner 2003, p. 55).

In American Jewish religious liberal (Reform and Conservative) circles, these issues are not insurmountable drawbacks. Already in the sixties Reform Rabbi Solomon B. Freehof confirmed in a *responsum* that "the exceptional nature and rights of the dead body do not stand in the way of the use of parts of the body for the healing of another body" (Freehof 1968). In his view, preserving human life is a sufficient justification for delaying burial, benefiting from the deceased and damaging mortal remains. Conservative Rabbi Elliot Dorff concurs with the position that organ donation honours the deceased and sanctifies God's name. He considers (post-mortem) organ donation an act of *chesed*, "an act done out of loyalty to one's fellow" (Dorff 1998, p. 222), to which he encourages Jews because of the shortage of organs. For his colleague, Rabbi Joseph Prouser, organ donation has an obligatory character, on the basis of the fundamental *mitzvah* of *pikuah nefesh* (preservation of life). He concludes: "When needed for lifesaving transplantation, withholding consent for postmortem tissue donation must be considered forbidden" (Prouser 2000a, p. 463). The 'Organ and Tissue Donation Card' published by the Jewish Conservative Rabbinical Assembly in 1996 stipulates that "one is obligated to permit post-mortem transplantation of his or her organs in lifesaving medical procedures and that withholding consent for such organ donation is contrary to Jewish law" (Prouser 2000b, p. 472).

Similarly, although he understood the fear and suffering of family members at the idea of mutilation, the late Orthodox Rabbi Moshe Feinstein did not depict organ donation as a desecration of the deceased but as a noble act (Jotkowitz 2008b, p. 708). After all, "the anguish a person feels at the thought of mutilation should be counterbalanced by the knowledge that by doing so he is saving a human life" (Tendler 1996, p. 122).

3.3.2 "You shall not kill"

Apart from the fear of mutilating and dishonouring the dead body, the fear of killing the organ donor comes to the fore in the Jewish debate on cadaver transplants. Therefore, the determination of death is thoroughly debated in the Jewish tradition. Indeed, the concern is about whether or not the organ donor is dead (according to medical and *halachic* criteria) at the moment organs are retrieved from his/her body.

Orthodox Rabbi David Bleich inclines to a threefold definition of death based on a nineteenth Century *responsum* of Rabbi Moses Sofer, who, responding to situations in which persons were mistakenly buried alive, stipulated three essential criteria of death: cessation of respiration and the absence of a heartbeat and movement (Freehof 1994, pp. 183–184; Sinclair 2003, p. 231). According to Bleich, as such ceasing of respiration is a necessary but insufficient criterion for death. In addition, absence of a heartbeat and any movement has to be determined (Bleich 1979b, pp. 282, 290; 1989). Thus, for him, a person who does not breathe spontaneously, but who manifests a heartbeat (as in the case of a brain-dead person) can in no circumstances be declared dead. Moreover, he declares that "advances in medical science and technology have no effect upon Jewish teaching with regard to the establishment of time of death" (Bleich 1981, p. 147).

As Bleich opposes brain death as *halachic* death (Bleich 1981, pp. 129–133; 1989), he seems to shut the door on organ transplantation, as nowadays (heart-beating) brain-dead organ donors are preferred. Although he does not mention it explicitly, non-heart-beating organ donation would seem to be an option for Bleich as long as this is uncontrolled (cardio-respiratory functions cease spontaneously). On the other hand, controlled non-heart-beating organ donation would probably be ruled out by him, as this would imply withdrawal of life-support (in case of inevitable death) (Vincent & Brimioulle 2009), which he would (most probably) condemn (Bleich 1978; 1979a; 1996).

Even though Jewish Orthodoxy has its rabbis who take an intense stand against brain death, a number of Jewish authorities (Orthodox and liberal) accept it. Orthodox Rabbi Moshe David Tendler is mentioned as an advocate of brain death as *halachic* death. He follows the opinion of his father-in-law, Rabbi Moshe Feinstein (1895–1986), who was considered an eminent *halachic* expert. In a *responsum* written in 1985, Feinstein declared that

the Harvard brain death criteria are in line with *halacha* (Tendler 1996, pp. 35–37). According to him, a brain death patient is similar to a decapitated patient. Both suffer complete damage of the brains and the brain stem. Similarly, according to Tendler, brain death is equal to "physiological decapitation" (1990, p. 7), which is in his opinion an acceptable *halachic* definition of death. After all, the cessation of heart beat is not a significant factor for determining death, but rather, the loss of the ability of spontaneous respiration. Rosner and Tendler argue that "if it can be definitely demonstrated that all brain functions including brain stem function have ceased, the patient is legally dead in Jewish law, because he is equated with a decapitated individuals *[sic]* whose heart may still be beating [. . .] Irreversible respiratory arrest is indicative of brain death" (1989 pp. 25, 27; 1997, pp. 55–72). Referring to *Mishnah Ohalot* 1:6, they compare the presence of heart beat in a brain-dead person with the death spasms of a decapitated animal:

> And likewise cattle and wild beasts… if their heads have been severed, they impart the impurity of death [as carcasses], even if they move convulsively like the tail of a lizard that twitches [after it has been severed from the body]. *(Mishnah Ohalot 1:6)*

As such, Tendler, in contrast to Bleich, would not conceive of the retrieval of organs from a brain-dead donor as murderous, thus not following the original position of his father-in-law, the late Rabbi Feinstein. Indeed, in his *responsa* of 1968 and 1978, Feinstein had defined heart transplantation as "double murder": murder of the donor, as his/her heart is removed before he/she is declared dead according to *halacha*; and murder of the recipient, because of the high risk factor of the operation at the time this *responsum* was written (Tendler 1996, pp. 37–38, 117–122). However, on the basis of Feinstein's endorsement of the Harvard brain death criteria in his *responsum* of 1985, Rosner contends that Feinstein has nuanced his position (Rosner 2003, p. 63). No longer did Feinstein look upon heart transplantation as double murder, as long as the donor was declared dead in line with medical and *halachic* criteria; he accepted brain death as *halachic* death, as long as the transplantation had a high success rate (Jotkowitz 2008b, p. 708).

In North American religious liberal (Reform and Conservative) Jewish circles, post-mortem organ donation does not seem to pose a problem and there is little or any dispute with regard to the acceptability of brain death. Both the Reform Central Conference of American Rabbis (CCAR) and the Conservative Committee on Jewish Law and Standards (CJLS) adopt brain death as *halachic* definition of death (CCAR 2002; Dorff 1998, p. 229; Jacob 1986; Nevins 2004; Prouser 2000a). In an extensive *responsum* approved by the Conservative CJLS, Nevins (2004) showed that brain death had substantial *halachic*

standing, referring to *halachic* sources which indicate that the ability to breathe ultimately defines the beginning and end of life.

3.4 Discussion

3.4.1 The value of human life

Apart from the fear of mutilating and dishonouring the dead body, the central problem in the Jewish debate on organ donation with heart-beating brain-dead donors seems to be the conflict between the commitment to save life and the concern not to take life. Indeed, preserving human life is a central Jewish commandment that takes precedence over all other religious regulations, except for the ban on the three cardinal sins: murder, idolatry and forbidden sexual behaviour (Bleich 1979c, p. 19; Freedman 1999, p. 143; Glick 1999, p. 45; Rosner 1999, p. 99). In this sense, Glick stresses that "life itself is not an absolute, nor even the ultimate highest value in the Jewish tradition" (1999, p. 45). Yet, violating Jewish law in order to save life is not only permitted, it is mandatory (Rosner 1984, p. 114; 1986, p. 35). Indeed, from the moment a person is born (every moment of) his/her life is regarded as being exceedingly precious (Bleich 1993; 2010; Rosner 1986, p. 35). Being God-created, each human life is unique and has an intrinsic worth. Consequently, in Judaism all human life is equal. Lives of young persons do not have more value than older people's lives. A disabled person has to be treated with as much respect as one who is not disabled (Rosner 1986, pp. 12, 35). Every human being possesses an irreplaceable dignity (Dorff 2003, p. 379). This summons them to take responsibility in God's creation. Jews not only shoulder responsibility for the world, they are also stewards of their lives and bodies (Glick 1999, p. 46). Jewish law warns human beings not to trifle with their life and body since these are not their property (Novak 2007, p. 93), but these are (conditionally) on loan from God and are to be treated with extreme care and utmost reverence (Dorff 1998, pp. 15–20; 2003, p. 378). As God's stewards, human beings are summoned to protect, preserve and save human life, wherever possible.

Thus, one may not expose oneself to danger and, where illness threatens human life, humans are urged to turn to medicine to seek recovery (Isaacs 1998, pp. 28, 32; Rosner 1999, pp. 99–100). The strong emphasis in Judaism on the fundamental value of human life and its preservation does not imply that the Jewish tradition is suspicious of new medical technologies and scientific progress. On the contrary, Judaism gives human beings, who are partners in God's creation (Dorff 1998, p. 29; Mackler 2003, p. 8), the *prima facie* obligation to make (positive) use of nature in order to prevent and treat disease. Thus, God's sovereignty and human freedom in creation are complementary. Although recognizing significant human freedom, Jews believe that, being God's stewards on earth, they are

urged to act according to God's example *(imitatio Dei)* and His will (Buber 1978, pp. 152–161; Mackler 2003, p. 6; Shapiro 1978, pp. 127–151; Sherwin 1990, p. 70), which is revealed to the Jewish people in the Torah.

The debate on organ transplantation and the use of brain-dead donors reflects Judaism's stress on human beings' freedom to make positive use of creation and on the importance of respecting human beings and preserving their lives. According to Bleich, human freedom in creation does not entail post-mortem organ donation making use of heart-beating brain-dead donors, which would be a clear violation of the commandment to save life. In his view, the donor's life would be illegitimately taken in order to save a person in need of an organ. Consequently, the act of organ transplantation would constitute sheer murder. Other Orthodox, Reform and Conservative rabbis involved in the North American debate on the issue, on the other hand, would state that retrieving organs from heart-beating brain-dead donors is not murderous and can be legitimately practiced within the framework of Jewish law. For them, this very practice is a clear fulfilment of the commandment to save and preserve life, which is mandated in Jewish law, and does not constitute a transgression of the Jewish prohibition to kill. In this sense, both positions stress and concur with the Jewish belief that humans are life-giving partners in God's creation and the appeal to act accordingly.

From this analysis it is clear that a specific religious understanding (in this case the huge value of human life resulting from a God-created condition) influences ethical opinions (in this case the acceptability or non-acceptability of the retrieval of organs from a heart-beating brain-dead donor). As such, Dorff and Newman (1995, p. 5; Newman 2005, p. 3) consider Jewish ethics to be an extension of Jewish theology. In the same way, Borowitz (1984, pp. 388–392) points to the fact that applied ethics rests on meta-ethics, assumptions about God and humankind.

3.4.2 Jewish ethics: diverse, casuistic and text-based

Jewish consensus on the acceptability of organ retrieval from brain-dead donors seems to be lacking (Reichman 2004, p. 67); especially in Orthodox Jewish circles where it seems to be a difficult topic of discussion (Inwald, Jakobovits & Petros 2000, pp. 1266–1268; Nevins 2004). The considerable disagreement on the topic between Rabbi Bleich and Rabbi Tendler does not rule out the possibility of (initiating) dialogue between the two perspectives. Indeed, difference of opinion and lively debate are not unusual in Judaism at all. The debate culture of Jews is reflected in the Talmud, and the Jewish folk saying "two Jews, three opinions" refers to it as well. Different rabbis often express divergent viewpoints on similar cases and issues. Being confronted with a (contemporary, ethical)

query, rabbis try to distil an answer turning to the rich Jewish textual tradition. Indeed, Judaism traditionally is a text- or law-based religion: guidance for everyday behaviour and conduct is found in the textual sources, which constitute *halacha* (Jewish religious law). In this way, when debating brain-dead organ donation, its acceptability is judged on the basis of Jewish textual and legal sources, for instance on the determination of death, which is clear from the debate sketched here.

Literally *halacha* means "the way" and contains "normative rules for conduct, laws that instruct the faithful on the sanctification of everyday life" (Neusner 2002, p. vii). The Jewish law comprises a corpus of texts, which includes the Torah, the Talmud, Codes of Jewish law and modern *responsa*. Being written in question and answer form, *responsa* try to deal with contemporary circumstances and specific cases, turning to precedents in Biblical and Rabbinic sources. Through these *responsa*, Jewish law continues to be alive and relevant to our time. Jewish ethical reasoning thus consists of an interpretation of these shared sources. "The Jewish ethicist discovers within God's revelation norms that can guide us in the present. The traditional rabbi, much like judges in a common law system, finds the proper precedents within this biblical and rabbinic literature and then applies them to the case at hand" (Newman 1992, p. 311).

Indeed, traditionally, Jewish ethical decision-making "favours a casuistry approach" (Steinberg 1994, p. 66), taking specific circumstances of individual cases into account and distilling relevant precedent cases in the Jewish textual tradition (Levin & Birnbaum 2000; Sinclair 2003, p. 7). In this sense, ethical guidelines are distilled from legislation (Jotkowitz 2010). Zoloth-Dorfman (1995) defines the method of Jewish ethics as a "casuistic deontology", stressing the centrality of rules and duties ('deontology') in Judaism, while acknowledging Judaism's sensitivity for case-specific contexts ('casuistic'), in which both inductive and deductive reasoning have their share (Breitowitz 1996). As such, when a rabbi or *halachic* judge (*posek*) is confronted with a case on organ donation or brain death, the specifics of the case at hand will be examined and confronted with analogical precedent cases found in the corpus of Jewish law (such as the textual sources cited in the above analysis). Apart from making use of this legal casuistry methodology, at the same time general Jewish rules, values and principles (such as the importance of life preservation and the prohibition to kill) are considered. In this sense, the rabbi or *posek* makes use of a "reflective equilibrium approach" (Jotkowitz 2010; Mackler 1995), being a holistic approach which allows the rabbi "to investigate detailed circumstances, explore analogies with other known cases, and consider the implications of general rules, values, and principles" (Mackler 1995, p. 179). In this back-and-forth reasoning approach (which for instance appears in rabbis' *responsa*), consideration of general principles, precedents and particular cases and insights go hand in hand. Thus, the acceptability of retrieval of organs

from heart-beating brain-death donors is judged on the basis of general Jewish principles, such as the high value of human life and its preservation, and relevant precedent cases in the Jewish textual and legal sources. At the same time, the bottom-up approach of Jewish (biomedical) ethics should be kept in mind: individual Jews' ethical dilemmas are considered on a case-by-case basis by their preferred rabbi.

3.4.3 Inter- and intra-denominational plurality

Inwald, Jakobovits and Petros (2000, pp. 1266–1268) point to the fact that rejection of brain death as criterion of death is the majority view in Orthodox Judaism. From our overview of North American Jewish viewpoints on death determination and organ transplantation using brain-dead donors we found a clear trans-denominational difference of opinion, namely between Orthodox Rabbi Bleich and the (more) liberal (Conservative and Reform) rabbis. Noticing this divergence we wonder whether these differences are understandable against the background of the specific characteristics of Judaism's main movements. Indeed, while Orthodox Jews generally consider *halacha* as essentially and exclusively divine, Reform Jews reject the divine origin of Torah and *halacha*. Conservative Jews occupy an intermediate position. They acknowledge that *halacha* plays a central role in Jewish ethics and life and they consider the Jewish tradition as the primary source of ethical values (Mackler 2000, p. 8). Yet, they see it basically as "a human institution" which "undergoes change and historical development like all human institutions" (Kellner 1978, pp. 16–17). While Orthodox Jews believe that *halacha* derives directly from the Torah, the direct, conclusive revelation of God's will, and while they consider it as "normative for all Jews in all places and at all times" (Kellner 1978, p. 16; 1995, p. 17; Zemer 1999, p. 41), Reform Jews acknowledge that Torah and *halacha* are "divinely inspired but at the same time the product of human thought" (Cohn-Sherbok 2004, p. 82). Thus, for them *halacha* is not an absolute binding norm which exceeds time and place (Cohen 2005, p. 6; Freehof 1960, p. 22; 1969, p. 7). Conservative Jews believe that Torah has a divine origin, but is significantly shaped by human beings when handed down and interpreted throughout the ages (Cohn-Sherbok 1996, p. 113; Küng 1992, p. 429; Mackler 2000, p. 7). Rabbis can reinterpret, challenge and change Jewish law keeping the purpose and spirit of the law and taking the historical context into account (Cohn-Sherbok 1996, pp. 117–121; Encyclopedia Judaica 1997). Having these specifics of Judaism's main movements in mind, it could be understandable that Orthodox Judaism occupies a more rigid and reluctant position towards organ donation using heart-beating brain-dead donors, a contemporary innovation of medical technology which obviously is not *as such* mentioned in Talmudic literature.

At the same time, the above description of the Orthodox, Reform and Conservative appreciation of Jewish law may not lead to a biased perception which catalogues Jewish Orthodoxy as static and Conservative and Reform Judaism as dynamic. Indeed, in our analysis we found Orthodox Jewish tolerance toward brain-dead organ donation. While Orthodox Rabbi Bleich shuts the door on post-mortem organ retrieval from brain-dead donors, by stipulating absence of heart beat, movement and spontaneous respiration as three essential (*halachic*) criteria for decease, his Orthodox colleague Rabbi Tendler clears the way for post-mortem organ retrieval from brain-dead donors by comparing brain death to physiological decapitation. While Tendler refers to *Mishnah Ohalot*, Bleich finds no precedent for brain death in Jewish law. To substantiate his position he refers to other *halachic* and, according to Nevins (2004), even cabbalistic sources. As such, diversity is exposed *within* the North American Orthodox Jewish branch. As shown, their difference of opinion goes back to a different handling of the Jewish textual sources. Additionally, it could be argued that Bleich stresses the need for caution with regard to *halachic* change, which is according to Mackler (2003, p. 7) a general tendency in Orthodox Judaism, while Tendler's position shows his acknowledgment that Jewish ethical reasoning needs development and innovation (Elon 1974, p. 53; 1999, pp. 6, 17), as it inevitably is related to daily life (and advancing medical sciences). Indeed, the age-long tradition of debate and discussion (reflected in the Talmud) points to the anything but static character of *halacha*. Yet, despite the need of the continuous development of Jewish law, the degree of *halacha*'s flexibility and progressivity seems to be disputed. This disagreement is reflected in the internal heterogeneity in the Jewish tradition with regard to concrete contemporary ethical dilemmas. As such, the inter- as well as intra-denominational pluralistic character of Jewish ethics, which also results from the lack of a centralised authority (in all branches of Judaism), despite the fact that "many rabbis have attempted to establish standards" (Cohn-Sherbok 2004, p. 85) for their community members, is thoroughly reflected in the discussion on organ donation and transplantation. All rabbis perceive their position as perfectly fitting in the framework of Jewish law, which is undoubtedly influenced by their specific understanding of it.

3.5 Conclusion

This review of North American religious Jewish perspectives on the issue of retrieval of organs from a heart-beating brain-dead donor reveals that two approaches are dominant. While liberal (Conservative as well as Reform) American rabbis appear to agree with the acceptability of organ transplantation, no unanimity is found among prominent Orthodox American rabbis. While Orthodox Rabbi David Bleich considers it murderous, and therefore irreconcilable with *halacha*, Orthodox Rabbi Moshe Tendler holds a

conflicting view which accords with the opinion of the liberal (both Reform and Conservative) rabbis. Both Orthodox rabbis hold a different interpretation of the position on brain death from the late Rabbi Feinstein, who has been granted the status of an eminent *halachic* expert.

On the one hand, the Jewish religious debate on organ transplantation with brain-dead donors illustrates the fact that world view and ethical standpoints are interrelated. The approaches reflect fundamental convictions of Jewish creation theology: the appeal to preserve and save human life, as human beings are created in God's image, and the stress on human freedom and his/her duty to make positive use of creation, as human beings are God's partners in creation. While these "meta-ethics" (Borowitz 1984, p. 388), views on God and humankind, generally are agreed upon (Borowitz 1984, p. 391), this does not result in a static and homogeneous applied Jewish ethics. After all, as illustrated, there is considerable disagreement on the content and extent of human freedom (in ethical and *halachic* respect) in creation.

On the other hand, the debate discloses the specificity of Jewish ethical decision making. Despite the dissension between Bleich and Tendler, the ethical reasoning of both Orthodox rabbis is theistic and *halachic*, as it is focussed on an interpretation of the Jewish textual tradition, starting with Torah, and seeking precedents in it, and based on *halachic* concepts, such as *pikuah nefesh* (preservation of life). In addition, Conservative and Reform rabbis consider it important that their viewpoints on brain death and organ donation are in harmony with the Jewish tradition, law and principles. As such, rabbis' ethical argumentation and reasoning (with regard to contemporary issues) draws on a common arsenal of values, principles and texts. Yet, these are not necessarily shared by everyone at all times. Thus, this common "casuistic deontology" approach (Zoloth-Dorfman 1995) does not clear the way for one unanimous Jewish opinion. After all, the way in which *halachic* concepts and Talmudic passages are applied to contemporary contexts, and the way in which the authority of *halacha* is perceived is divergent. Moreover, the bottom-up approach of Jewish (medical) ethics has to be kept in mind. Questions from individual Jews are confronted by *halachic* experts and rabbis on a case-by-case basis. Respecting this inter- and intra-Jewish denominational heterogeneity, outlining the Jewish view on contemporary ethical dilemmas, such as organ retrieval from heart-beating brain-dead donors is simply impossible. As such, retrieval debates reflect the Jewish culture of debate and discussion.

4 "There is a time to be born and a time to die" (Ecclesiastes 3:2a). Jewish Perspectives on Euthanasia

4.1 Introduction

The Hebrew Bible frequently confronts us with the finiteness of man's existence. Not only *Genesis* 3:19b provides this irrefutable wisdom, when uttering the verse "For dust you are and to dust you will return", a few books further also *Ecclesiastes* 3:1-2a reminds us of being mortal beings, stating: "There is a time for everything and a season for every activity under heaven: there is a time to be born and a time to die". Death is an inescapable fact. It is an absolute truth. The certainty of death, however, is covered up with mysteries. Much as our death is certain, the circumstances in which we will die are not predictable. Death's time, place and circumstances – as a result of old age, accident or illness – are beyond reach of human knowledge. "It is in God's hands", so would many religious people – whether Christian, Muslim or Jewish – say. As finite beings, we all are susceptible to death and illness.

Today, the realm of death and illness has changed. During the past decades, biomedical technology has developed significantly. As a result of this medical revolution, the power of humankind within the domain of life and death has increased. Making use of available biomedical technology human beings are not only able to control and cure diseases, but also to regulate their own life project, even their own death. Consequently, during recent years we are all the more confronted with ethical challenges and questions. Human beings, adhering to a specific world view or religious tradition, deal with these ethical issues in various ways. One's world view, one's conception of transcendence and immanence – in other words, the way everything *is* according to a situated human being – influence one's opinion on what *ought* to be (Newman 2005, pp. 18–19; Gielen, Van den Branden & Broeckaert 2009a), for example what ought to be done when confronted with terminal illness and unbearable pain.

The aim of this article is to explore Jewish perspectives on a most pressing contemporary bioethical issue: euthanasia. This quest is considered within the broader framework of the specificities of Jewish (biomedical) ethics and its methodology. Therefore, this article will first shed a brief light on the Jewish religious tradition as such and attention will be paid to religious convictions and ethical reasoning of the three largest branches of Judaism: Orthodox, Reform and Conservative. After this short introductory note, the central topic of this article is addressed: how does the Jewish tradition cope with euthanasia? First, Jewish textual sources are quoted, which are usually referred to and

interpreted when the ethical question of euthanasia is addressed. Next, we show how different rabbis – we made a selection of prominent rabbis and *poskim* (specialists of Jewish law) from the three largest Jewish branches – reach diverse, even opposite, conclusions with regard to euthanasia, based on their interpretation of these sources. In this way, the threefold aim of this article is met: (1) presenting a non-exhaustive overview of Jewish perspectives on euthanasia, which reflects (2) the characteristic text-centeredness of Jewish (bio-)ethical reasoning and (3) Judaism's essential diversity and the specific features of its largest branches.

Although Reconstructionism is a full-fledged Jewish movement in the United States, within the scope of this article, we decided not to include Reconstructionist reflections on the matter at hand, as the Reconstructionist movement is substantially smaller than the Orthodox, Reform and Conservative branch of Judaism, considered on a world wide as well as American scale. The 2000-2001 National Jewish Population Survey (NJPS) indicates that only 2% of American Jews considers themselves to be Reconstructionist, in contrast tot 13% Orthodox, 26% Conservative and 34% Reform (Ament 2005). Yet, for Reconstructionist reflections on end-of-life practices and ethics, consult Teutsch (2005) and 'Behoref Hayamim' (Reconstructionist Rabbinical College 2002).

4.2 Definition of Jewish identity

Since the purpose of this article is to present Jewish religious opinions on euthanasia, this article covers only a small part of the Jewish world total, for only a minority of the approximately 14 million Jews worldwide can be characterized as religious. Often, it is assumed that because a person is a Jew, he/she adheres to the Jewish religion. Brachfeld (2000, p. 9), however, indicates that only 15-20% of all Jews is religious. Yet, exact figures on this do not exist and only estimations can be indicated. Still, it can be argued that the Jewish religion in fact "divides the Jewish people today, perhaps almost as much as it divides Jews from non-Jews" (de Lange 2000, p. 2). The majority of contemporary Jews are only Jewish in an ethnical sense: their Jewishness has nothing to do with religion or with God. These non-religious Jews are secular Jews, whose daily life choices are not guided by the world of Jewish sacred texts. "Some of these Jews may be atheists; many may be simply indifferent to Judaism, about which they know very little. Many nonetheless continue to regard themselves as 'good Jews'" (Neusner 1975, p. 6). Non-religious Jews perceive the Jewish faith as a "traditional, folkloristic, mystical or historical part of the ancient culture" (Brachfeld 2000, p. 9). Religious Jews, on the other hand, adhere to a specific world view and way of life and are embedded in a religious community (Neusner 2006, pp. 2–3). For

them God is central, and their daily life choices are guided by the path God stipulated for them in prescriptions and commandments (*mitzvoth*). Nevertheless, as will appear in this article, representing religious Judaism one-sided would do harm to its essential variety.

4.3 The (heterogeneous) specificity of Jewish ethics

Indeed, characterizing religious Judaism is utmost delicate. Schulweis (1995, p. 25) expresses this inner-Jewish heterogeneity through the symbol of "a broad river with multiple branches running into the sea". The largest Jewish branches are Orthodox, Conservative and Reform Judaism. Before turning to this in detail, the characteristic properties of Jewish ethics are highlighted.

Jewish (biomedical) ethics – like all ethics – starts from an issue which is experienced as problematic. The specificity of Jewish ethics consists in providing an answer to this question by addressing religious authorities, whose writings are preserved in traditional Jewish literature. In other words, confronted with a (contemporary) ethical question, rabbis address the rich Jewish tradition (of textual sources) in order to provide an answer. Jewish ethical reflection arises out of specific cases: individual Jews – confronted with an ethical dilemma – can ask a rabbi for guidance. In this sense, Jewish ethics is case-based and concentrated on concrete human behavior rather than on general claims of faith and theology (Kellner 1978, p. 5): "It's a tradition of ongoing questioning rather than one of absolute theological law passed down from above" (Goldsand, Rosenberg & Gordon 2001, p. 221). Noticing this, Jewish ethics makes use of a bottom-up approach.

As Jewish revelation theology indicates, traditionally Judaism has been a law-based religion, with virtually all aspects of life governed by a comprehensive system of laws, called *halacha* (Newman 1992). Literally, *halacha* means 'the way' and is referred to as the Jewish religious law which can be defined as follows: "normative rules for conduct, laws that instruct the faithful on the sanctification of everyday life" (Neusner 2002, p. vii). The Jewish law consists of a corpus of texts, ranging from the Torah, the Talmud, Codes of Jewish law, to modern *responsa* – written in question (*she'eilah*) and answer form (*teshuvah*) – which try to apply Talmudic discussions and regulations to contemporary circumstances and specific cases. Noticing this, Jewish legal and ethical reasoning consists of an interpretation of these sources. "The Jewish ethicist discovers within God's revelation norms that can guide us in the present. The traditional rabbi, much like judges in a common law system, finds the proper precedents within this biblical and rabbinic literature and then applies them to the case at hand" (Newman 1992, p. 311).

Of course, in this process interpretation plays a crucial role, as well with regard to getting acquainted with the case at hand, as with regard to distilling relevant literature and

principles. The complexity and the contextual nature of *halachic* questions implies that there is a variety of (*halachically* valid) answers to one question. The heterogenic characteristic of Jewish ethics is also influenced by the way in which the authority of *halacha* is perceived. There exists – within Judaism – a range of opinions on the normativity and authority of these traditional texts. As a result, Jewish ethical reasoning depends on rabbis' and ethicists' concrete interpretive process and on the perceived status of *halacha*, as either normative or advising (Ellenson 1995). Nevertheless, the ethical decision-making process is always – exclusively or not exclusively – *halachic* (Mackler 2003, p. 45; Jage-Bowler 1999, p. 219).

4.4 JEWISH BRANCHES

The heterogenic characteristic of Jewish ethics has to be situated against the background of an inner-Jewish heterogeneity. In response to modernity and Enlightenment in nineteenth century Germany different movements have originated within the Jewish tradition, whose ascribing significance to the religious tradition when answering ethical questions is quite divergent. Yet, the three largest branches of the Jewish faith tradition – Orthodox, Conservative and Reform – even reflect an inner diversity. Nevertheless it is possible to describe some common tendencies, with regard to theological convictions and ethical reasoning, within each movement. Given that few contemporary Jews world wide and even in the United States consider themselves to be Reconstructionist (Ament 2005) we choose explicitly to stick to the three largest movements of Judaism and not to expand on Reconstructionist Judaism.

The three branches can be situated on an axis, on which the Orthodox and Reform movement constitute the opposite extremes, while the Conservative branch occupies an intermediate position. The Orthodox branch, which originated in response to the Reform movement to protect the integrity of the Jewish faith, is situated on the right side of the axis, being the most traditional of the largest movements, as it considers the Torah as the direct and definite revelation of God's will (Kellner 1978, p. 16). Orthodox Jews believe that God has revealed the Torah to Moses literally, word by word, "in a form identical to our printed text" (Mackler 2000, p. 7). Consequently, in their opinion, Torah and Talmud are divinely inspired and revealed and are essentially unchanging and immutable. Concerning ethics, *halacha* is considered as being the will of God, normative for all Jews, living in all times and at all places (Kellner 1995, p. 17; Zemer 1999, p. 41).

Confronted with contemporary ethical issues, Orthodox rabbis or *poskim* (*halachic* specialists) address the *halacha* as an absolute divine norm, believing that Jewish law has to guide Jews through their lives and daily life choices. Their traditional ethical decision-making process is often described as a legal model or as "halakhic formalism" (Ellenson

1995, p. 130), consisting of *halachic* analysis resulting in interpretations that become normative and binding on Orthodox adherents. Yet, the Orthodox Jewish community is not monolithic, taking for instance the lack of a coordinating Orthodox Jewish body, and consequently, the lack of definitive, authoritative *halachic* rulings into account. All rabbis have the right to investigate an ethical dilemma and to give a (binding) answer through an interpretation of the sources. The weight ascribed to this decision depends on different factors, for instance the reputation of the rabbi as specialist or *posek* (in a certain *halachic* domain) (Flancbaum 2001, p. 31). Anyhow, rabbinic authority is most central (Mackler 2003, p. 52).

On the other side of the spectrum, on the left side of the axis, Reform Jews hold to a dynamic and progressive revelation. Torah is mainly seen as a human writing, based upon human beings' understanding of God's will. Similarly, the Talmud is considered not to be divine, but human in origin, as a human analysis of the laws of the Torah as they were understood in Talmudic times (Jacob 1987, p. xx). As the "God-given authority" (Freehof 1960, p. 21) of rabbinic literature is denied, Reform Jews reject *halacha* as eternal and universal norm which exceeds space and time (Freehof 1960, pp. 5, 20). Indeed, the early Reform movement was even "averse to the rabbinical literature, the Talmud and the codes, which were the source of the rabbinical authority" (Freehof 1960, p. 15), stressing its biblical and prophetic inspiration. The *halachic* tradition was viewed as "rigid and arcane, a relic of another time" (Newman 2005, p. 133). In the contemporary Reform branch, this antinomian tendency "remains part of the Reform perspective" (Jacob 2004, p. 72), but it is weakened to a large extent. Nowadays, looking for an answer to a contemporary ethical question, *halacha* is addressed. It can offer guidance to individuals but has no binding authority (Freehof 1960, pp. 21–22; 1969, p. 7; Cohen 2005; Newman 1995a, p. xxi). Although a rabbi can give advice, "individual autonomy remains predominant" (Mackler 2003, p. 52; Plaut & Washofsky 1997, p. xv). At the same time, Reform thinkers warn for unbridled autonomy (Plaut & Washofsky, pp. xvii–xxi) and plead for a "harmony between discipline and freedom, between loyalty and individuality" (Freehof 1974, p. 6). Thus, the *responsa* of the Central Conference of American Rabbis (CCAR) try to guide and advise Reform Jews with regard to their daily (autonomous) life choices (Freehof 1960, p. 22; Plaut & Washofsky 1997, p. xxviii).

The Conservative movement, which originated as a traditionalist response to Reform Judaism, occupies an intermediate position. It constitutes a compromise between the Orthodox and Reform branch. Torah and Talmud are regarded as both divine in origin, but significantly shaped "by human reception, transmission and interpretation" (Mackler 2000, p. 7; 2003, p. 48; Küng 1992, p. 429). In contrast to Orthodox Judaism, Conservative Jews do not consider Torah as a literal account of God's words. The Jewish people's divine

experiences are the source and essence of *halacha*, which is liable to changes and historical developments. Yet, although being a historical developed entity, *halacha* plays a definite and normative role. Conservative Jews assume that qualified rabbis can reinterpret and change Jewish law, as the historical context of the Biblical times does not necessarily reflect our contemporary context. The rabbi is looked upon as a *halachic* guide, who interprets Jewish law from a contemporary perspective, taking into account its historical development. In this sense, the ethical model triumphing in this movement is "tradition and change" (Küng 1992, pp. 430–432; Mackler 2000, p. 7). Within the Jewish Conservative community the Committee on Jewish Law and Standards (CJLS) of the Rabbinical Assembly, decides upon *halachic* questions. The CJLS can proclaim official *halachic* positions of the Conservative movement. Yet, also deviant opinions, without official recognition of the committee are tolerated. Moreover, as stated on the website of the Rabbinical Assembly, the advice of the local rabbi has to be taken into account. When deciding upon an ethical dilemma the individual's and rabbi's authority are usually balanced (Mackler 2003, p. 53).

Summarizing, within each movement *halachic* literature is addressed when rabbis are confronted with an ethical dilemma. Diversity between the Jewish branches does not consist in a consultation or rejection of *halacha*, but in the way *halacha* and its interpretation is perceived, as binding or advising. Simultaneously, we must beware of giving a biased and simplistic portrayal, as Reform, Conservative nor Orthodox Judaism are entirely monolithic. The Reform branch has a non-*halachic* side (Jacob 2004) and alternative approaches to Jewish ethics are found in all movements (Newman 1995b, p. 138–147). Anyway, Jewish ethics is founded on the Torah as primary source – but not necessarily exhaustive or exclusive – and presupposes reference to the Jewish tradition (of interpretation) (Newman 2005, p. 117).

4.5 JEWISH RELIGIOUS SOURCES ON EUTHANASIA

In order to give an overview of Jewish opinions on euthanasia it is essential first to quote some Jewish religious texts which are widely adopted and interpreted when rabbis are discussing euthanasia as an ethical topic. In the next section of this article an overview of Orthodox, Conservative and Reform opinions based on these textual sources is presented. Working in this way we meet the characteristic property of Jewish ethics, namely searching an answer to a concrete ethical concern starting from the textual tradition. Often, from one textual source diverse, even contradictory, opinions emerge through different interpretations.

The first important source, *Semahot* 1:1–4, is described within the literature of Jewish medical ethics as the laws of *goses*. Within Jewish religious law a *goses* is defined as a

person who is expected to die within 72 hours or three days and is recognizable by the death rattle (Jakobovits 1959, p. 349). Because of the weakened condition of the *goses* and "in order to avoid any risk that an individual caring for a *goses* would inadvertently shorten his or her life and be liable to capital punishment" (Kinzbrunner 2004, p. 564), the care of the moribund person was enclosed with some strict rulings, such as the prohibition to touch a *goses*. The Jewish law considers a *goses* as a living person in every respect and, being even in his last moments of life, he has to be treated according to this living status (Jakobovits 1959, p. 121; Sinclair 1989, p. 9; 2003, p. 181).

> A dying man is considered the same as a living man in every respect. [...] His jaws may not be bound, nor his orifices stopped, and no metal vessel or any other cooling object may be placed upon his belly until the moment he dies, as it is written, Before the silver cord is snapped asunder, and the golden bowl shattered, and the pitcher is broken at the fountain (Eccl. 12:6). He may not be stirred, nor may he be washed, and he should not be laid upon sand or salt, until he dies. His eyes may not be closed. Whosever touches him or stirs him sheds blood. Rabbi Meir used to compare a dying man to a flickering lamp: the moment one touches it he puts it out. So, too, whosever closes the eyes of a dying man is accounted as though he has snuffed out his life. There may be no rending of clothes, no baring of shoulders, nor eulogizing, and no coffin may be brought into the house, until the moment he dies. *(Semahot 1:1–4)*

The second important rabbinic source often cited and interpreted when rabbis and ethicists reflect on euthanasia is *Bavli Avodah Zarah* 18a, telling about the martyrdom of Rabbi Hanina ben Teradion who was executed by the Romans because of ignoring a Roman prohibition to study and teach the Torah.

> Straightaway they took hold of him, wrapt him in the Scroll of the Law, placed bundles of branches round him and set them on fire. Then they brought tufts of wool, which they had soaked in water, and placed them over his heart, so that he should not expire quickly... [...] 'Open then thy mouth' [said they] 'so that the fire enter into thee.' He replied, 'Let Him who gave me [my soul] take it away, but no one should injure oneself.' The executioner said to him, 'Rabbi, if I raise the flame and take away the tufts of wool from over thy heart, will thou cause me to enter into the life to come?' 'Yes,' he replied. 'Then swear unto me' [he urged]. He swore unto him. He thereupon raised the flame and removed the tufts of wool from over his heart, and his soul departed speedily. *(Avodah Zarah 18a)*

Bavli Ketubot 104a is another Talmudic source often cited regarding euthanasia, a story about the death of Rabbi Judah HaNasi, the compiler of the Mishnah.

> On the day when Rabbi died, the rabbis decreed a public fast and offered prayers for heavenly mercy. [...] Rabbi's handmaid ascended the roof and prayed: 'The immortals desire Rabbi [to join them] and the mortals desire him [to remain with them]; may it be the will [of God] that the mortals may overpower the immortals.' When, however she saw how often he resorted to the privy, painfully taking off his tefillin and putting them on again, she prayed: 'May it be the will [of the Almighty] that the immortals may overpower the mortals.' As the rabbis incessantly continued their prayers for [heavenly] mercy she took a jar and threw it down from the roof to the ground. [For a moment,] they ceased praying, and the soul of Rabbi departed to its eternal rest. *(Ketubot 104a)*

4.6 "Two Jews, three opinions". Jewish opinions on euthanasia

The Jewish folk saying "two Jews, three opinions" illustrates the wide diversity of opinions within Judaism on a range of topics. Also with regard to euthanasia there seems to be no definitive Jewish stance. Although rabbis belonging to different Jewish movements base their judgments on common Jewish sacred texts – such as those cited above – they often do not reach the same conclusion (Ellenson 1995). Reviewing opinions and interpretations with regard to euthanasia of prominent American Orthodox, Conservative and Reform rabbis, who have (extensively) published on the matter, a diversity between and within the largest Jewish branches appears. In contrast to the Conservative and Reform branch of Judaism, in the Orthodox movement, reviewing the literature, we did not find any advocate of euthanasia.

Given the central aim of this article – (1) reflecting upon the specific, text-centered nature of Jewish (bio-)ethical reasoning, by (2) describing diverse Jewish viewpoints on euthanasia – it would not be feasible nor useful to give an exhaustive overview of virtually all opinions of important *poskim*, rabbis and non-rabbinic academic scholars with regard to the issue at hand. Therefore, we made a selection of opinions of prominent rabbinic figures.

4.6.1 Orthodox movement

4.6.1.1 Rabbi David Bleich's arguments against euthanasia

On the Orthodox side Rabbi David Bleich is a radical opponent of euthanasia and an advocate of an absolute sanctity-of-human-life approach. Consequently some characterize him as a "vitalist" (Thomasma 1999, pp. 59–60; Cohen-Almagor & Shmueli 2000, p. 125). According to Bleich (1981, p. 135; 2010, p. 25) not only human life in general is of infinite and inestimable value, but even every moment of life, since "the quality of life which is preserved is never a factor to be taken into consideration" (Bleich 1979c, p. 19). According to him this is illustrated by the Talmudic assertion that even on Sabbath efforts to free a victim buried under a collapsed building must be continued even if the victim is found in such circumstances that he cannot survive longer than a brief period of time. Additionally, he refers to a passage in tractate *Sanhedrin* (37a) of the Babylonian Talmud which provides most eloquently the view that the value of human life is extremely important and takes precedence over virtually all other considerations:

> For this reason man was created alone, to teach that whosever destroys a single soul of Israel, scripture imputes [guilt] to him as though he had destroyed a complete world; and whosever preserves a single soul of Israel, scripture ascribes [merit] to him as though he had preserved a complete world.

According to Bleich this source provides the basis of *pikuah nefesh*, the duty to save and preserve human life. This commandment is based on the Jewish religious conviction that human beings are only stewards of their body: "never is he [man] called upon to determine whether life is worth living – this is a question over which God remains the sole arbiter" (Bleich 1979c, p. 19). As God's creation, we do not own our human body. Instead, it is God's property. Consequently, in Bleich's opinion "man does not enjoy the right of selfdetermination with regard to questions of life and death" (1979a, p. 269). Human life has no instrumental, but an intrinsic value. It is a "bonum per se" (Bleich 1993). Human beings' task is to preserve, to dignify and to hallow this divine gift.

Bleich interprets the Jewish religious source *Semahot* 1:1–4 literally. His conclusion when reading it is: "Accordingly, any movement or manipulation of the dying person is forbidden" (Bleich 1981, p. 137) since the candle's flickering flame risks to become extinguished by the slightest touch. Briefly referring to a codification of Rabbi Moses Isserles in this regard, Bleich takes the view that the death of a *goses* may not be speeded, but there is also "no obligation to perform any action which will lengthen the life of a patient in this state" (Bleich 1979c, p. 33). When reading *Bavli Ketubot* 104a he recognizes

the fact that the female servant prayed for the death of Rabbi Judah. Following some rabbinic authorities, Bleich concludes that "although man must persist in his effort to prolong life, he may, nevertheless, express human needs and concerns through the medium of prayer" (Blelch 1978, p. 302; 1979a, p. 271; 1981, p. 143). Further on he states that there is "no contradiction whatsoever between acting upon an existing obligation and pleading to be relieved of further responsibility [...] But ultimately the decision is God's, and God's alone." (Bleich 1978, p. 302; 1979a, p. 271; 1981, p. 143). Taking these textual interpretations into account Bleich is of the opinion that the practice of euthanasia is contrary to the teachings of Judaism. According to Bleich, in Jewish law every positive act which hastens death is equated with murder, "no matter how laudable the intentions of the person performing the act of mercy-killing may be" (Blelch 1981, p. 136). Despite the noble intent and "no matter how hopeless or meaningless continued existence may appear to be in the eyes of the mortal perceiver" (Bleich 1993, p. 139), the life of a human being may be reclaimed only by the Author of life and death.

4.6.2 Conservative movement

4.6.2.1 Rabbi Elliot Dorff & Rabbi Avram Reisner: fierce opponents of euthanasia

Within the Conservative branch Rabbis Elliot Dorff and Avram Reisner are both opponents of euthanasia. How do they interpret the eited Jewish sacred sources? First of all, considering the laws of *goses*, they not only mention tractate *Semahot* 1:1–4, but they also take – more extensively than Blelch – the codification of this tractate by the sixteenth century Rabbi Moses Isserles into account:

> It is forbidden to do anything to hasten the death of one who is in a dying condition.... If, however, there is something that causes a delay in the exit of the soul, as, for example, if near to this house there is a sound of pounding as one who is chopping wood, or there is salt on his tongue, and these delay the soul's leaving the body, it is permitted to remove these because there is no direct act involved here, only the removal of an obstacle (quoted in Dorff 1998, p. 199).

Following this, Dorff and Reisner make a distinction between euthanasia and the withholding and withdrawing of life-sustaining treatment. Latter is (more) acceptable, whereas the former is strictly forbidden. In other words, according to these rabbis, a distinction is to be made between the maintaining and prolongation of human life on the one hand and the prolongation of the death process on the other. Although the Jewish tradition asks for the pursuit and maximization of life, the irrefutable wisdom "there is a

time to die" of *Ecclesiastes* 3:2a must be respected: "we are not to stand in the breach to ward off death in its time" (Reisner 2000b, p. 252). In the opinion of Dorff (2000a, p. 313) the objective of medical care is to act for the patient's benefit. Consequently the pain of the patient can prevent doctors to decide to continue aggressive treatment when there is no reasonable chance of recovery from a terminal illness.

Referring to *Bavli Avodah Zarah* 18a, the story about the martyrdom of Rabbi Hanina ben Teradion, Reisner (1991, p. 55; 2000b, p. 243) urges us to keep in mind those words of Rabbi Hanina affirming the traditional Jewish prohibition to hasten death and the *mitzvah* of self-preservation: "Let Him who gave me [my soul] take it away, but no one should injure oneself." Although Dorff does not quote this source literally, he states that there is no inviolable and unexceptionable rule in Jewish law that all life is sacred. The – Orthodox – interpretation of Jewish sacred sources that even small moments of human life – whatever its quality – must be preserved is "a mistaken reading of tradition" (Dorff 2000a, p. 312). Dorff stresses that there are cases in which Jewish law requires us to give up life or to take one, for instance when Jews are forced to one of the three cardinal sins – idolatry, murder and forbidden sexual relations, such as incest and adultery – Jewish religious law commands its adherents to choose death. In the case of Rabbi Hanina - a case of martyrdom – taking one's life is an act of *Kiddush ha-Shem*, the sanctification of God's name.

The message Reisner distills out of *Bavli Ketubot* 104a resembles Orthodox Rabbi Bleich's interpretation: as human beings we are called to follow the tracks not only of the pro-life praying rabbis surrounding Rabbi Judah, but also of Rabbi Judah's handmaid by responding mercifully in situations of suffering, for instance by requesting God that He would offer a quick and merciful death to the sufferer (1991, p. 56). Without denying the efficacy of the prayer, Reisner (2000b, p. 245) does affirm clearly that not the female servant ended the life of Rabbi Judah, but God did. God was the final arbiter, who determined his death.

Taking these traditional Jewish sources into consideration, Conservative Rabbis Dorff and Reisner both conclude that euthanasia is forbidden, while – in certain circumstances and under certain considerations – it may be permitted to withhold and withdraw a life-sustaining treatment.

4.6.2.2 Rabbi Byron Sherwin's pro-arguments

Within the Conservative movement, Rabbi Sherwin declares himself to be an advocate of euthanasia. Taking a look at the Talmudic story of the martyrdom of Rabbi Hanina he concludes that life is precious and of intrinsic value, but there are exceptions to

the preservation of life, for example killing in self-defense. This "and other forms of 'justified homicide' have been sanctioned as 'necessary evils' by rabbinic tradition" (Sherwin 1995, p. 365).

Whereas in various situations killing another human person may be justifiable and permissible according to Jewish Law, in instances where martyrdom is indicated, killing oneself, allowing oneself to be killed, or killing another person, may be required by Jewish Law. Precisely because martyrdom represents the ultimate expression of the human sacrifice to God (*Kiddush ha-Shem*), it has been considered throughout most of Jewish history to be the most exalted virtue – transcending the obligation to preserve human life at any cost (Sherwin 2000, p. 41).

According to Sherwin *pikuah nefesh* – preservation of life – is not always an absolute moral imperative (1990, p. 93). To substantiate this thoroughly he makes use of another Talmudic source, which tells the story of 400 children drowning themselves in the sea to prevent being abused by their capturers.

> On one occasion four hundred boys and girls were carried off for immoral purposes. They divined what they were wanted for and said to themselves, If we drown in the sea we shall attain the life of the future world. The eldest among them expounded the verse, *The Lord said, I will bring you again from Bashan, I will bring again from the depths of the sea. 'I will bring again from Bashan,'* from between the lions' teeth. *'I will bring again from the depths of the sea,'* those who drown in the sea. When the girls heard this they all leaped into the sea. The boys then drew the moral for themselves, saying, If these for whom this is natural act so, shall not we, for whom it is unnatural? They also leaped into the sea. Of them the text says, *Yea, for thy sake we are killed all the day long, we are counted as sheep for the slaughter. (Bavli Gittin 57b)*

Taking these sources into account, Sherwin interprets them meaning: "to avoid sufferings certain to result in death, it is permitted to take one's own life, and in such instances it is required to violate the injunctions against injuring oneself" (2000, p. 50). Based on a few additional sources, such as *Bavli Ketubot* 104a – which, according to him, indicates the permissibility of actively praying for death (Sherwin 1998, p. 93) – and *Bavli Pesahim* 75a uttering the verse: "therefore, choose an easy death for him", Sherwin concludes that euthanasia may be a *halachic* option (Sherwin 2000, pp. 35, 61). Apart from these, a very important source within his pro-euthanasia argumentation scheme is a passage in tractate *Sanhedrin* (78a) of the Babylonian Talmud, making a distinction between a *goses* and a *terefah*. According to Jewish law a *terefah* is a terminally ill person, not yet in the process of dying, whereas a *goses* is a dying person, who is expected to die within 72 hours

or three days, as a result of illness or of old age. Consequently, not every *goses* can be considered a *terefah*. This seemingly tiny distinction is crucial within Jewish law, which states that a person who kills a *terefah* is not liable to punishment – it is only in God's power to judge and to punish him – because a *terefah* is considered to be a *gavra katila*, a person who is already dead. His blood is considered to be less red in comparison with that of a *goses*, who is regarded as a living person, though in a moribund state in which death is imminent (Sinclair 1989, pp. 19–69). Taking Jewish law into account on this remarkable point, Sherwin concludes that a physician may be legally blameless for practicing euthanasia.

Conscious of the fact that he is a stranger in his midst when defending this pro-euthanasia opinion, Sherwin (2000, pp. 60–61) concludes:

> In view of contemporary realities, I have felt it necessary to defend a position within the framework of classical Jewish sources that would justify active euthanasia in at least certain circumstances. I believe that patients whose last days are overwhelmed with unbearable agony, who have no hope of recovery, who have irreparable organ damage, and who have exhausted all medical remedies should be able to advocate and to practice active euthanasia without feeling they are criminals [...] To be sure, Judaism instructs us to 'choose life' (Deut. 30:19), but Judaism also recognizes that 'there is a time to die' (Eccles. 3:2).

4.6.3 Reform movement

4.6.3.1 Central Conference of American Rabbis (CCAR) rejects euthanasia

On the basis of the *goses* laws, mentioned in *Semahot*, in its *responsa*, issued by several rabbis (Freehof, Jacob, Bettan, Plaut and Washofsky) the Reform Central Conference of American Rabbis (CCAR) asserts that a human being has no right of ownership over his/her body, and consequently has no authority to bring his/her life to a premature end (Freehof 1960, pp. 117–122; 1971, pp. 197–303; 1983, pp. 257–260; Bettan 1983, pp. 261–270; Jacob 1987, pp. 138–139; 1995a, pp. 127–130; 1995b, pp. 131–133; 1998, pp. 153–156; Plaut & Washofsky 1997, p. 337–363). Their holding to a prohibition of euthanasia is also based on the interpretation of the Talmudic sources mentioned earlier.

In the CCAR's responsum 'On the Treatment of the Terminally Ill' (Plaut & Washofsky 1997, pp. 337–363), *Bavli Avodah Zarah* 18a and *Bavli Ketubot* 104a are interpreted. With regard to the source narrating the martyrdom of Rabbi Hanina, *responsa* of the CCAR argue as follows. At first glance, the behavior of Rabbi Hanina in this story is

contradictory. On the one hand, Rabbi Hanina refuses to open his mouth and let the fire enter there, in other words he refuses to hasten his death. On the other hand, Rabbi Hanina asks his executioner to remove the wet tufts of wool and to raise the flame and promises him life into the world to come. According to the CCAR (Plaut & Washofsky 1997, p. 357) this is but an apparent contradiction, since we have to keep in mind that this story is a case of martyrdom. Consequently, this story cannot be interpreted as if Rabbi Hanina can appoint the executioner to do anything, for the guard is not the rabbi's agent but his executioner – he is the agent of the Roman authorities. Considered in this way, Rabbi Hanina does not act to participate directly in the hastening of his death, either by his hand or through an agent.

Regarding *Bavli Ketubot* 104a the CCAR (Plaut & Washofsky 1997, p. 358) asserts that there is a moral difference between taking action to hasten a person's death and withdrawing treatment so as to allow death to occur. The death of Rabbi Judah was not a result of action, but of inaction. Not the servant's prayer for his death causes him to die, but the ceasing of praying by the surrounding rabbis. Moreover, this source does not provide guidance for euthanasia, but it does for the withholding and withdrawing of life-sustaining treatment, for one may not delay death unnecessarily. Importantly, Freehof (1960, p. 119; 1971, p. 200; 1983, p. 258) and Jacob (1987, p. 139) add that asking God to be relieved of suffering is permissible.

Reacting against the minority of Jewish advocates of euthanasia on the basis of Jewish law the CCAR declares: "As Reform Jews we consider ourselves free to ascribe 'new' Jewish meanings to our texts... in this case, though, we fail to see why we should do so... The unequivocal voice of the halakhic literature renders it difficult to sustain an argument, based upon the citation of a few stories from the Bible and the Talmud, that the 'Jewish tradition' permits euthanasia" (Plaut & Washofsky 1997, p. 340). Similarly, in their *responsa* Rabbi Bettan (1983), Freehof (1983) and Jacob (1987; 1995a; 1995b; 1998) affirm that (active) euthanasia is irreconcilable with the Jewish tradition.

4.6.3.2 Rabbi Leonard Kravitz and Rabbi Peter Knobel accept euthanasia

In spite of the clear statement uttered by the CCAR, the Reform movement has its convinced supporters of euthanasia. We highlight the argumentation of two Reform rabbis, Leonard Kravitz and Peter Knobel. Citing the laws of *goses* and the additional rabbinic codification of Rabbi Moses Isserles, to which Bleich, Dorff and Reisner too refer, Kravitz concludes that stopping the woodchopper or removing the salt from the tongue of the dying person are actions being done: "one must go to the wood chopper to tell him to stop and one must reach into the patient's mouth to remove the salt. There is certainly an act

involved!" (1995, p. 18). Stating this he rejects the distinction often made by rabbis – see also the argumentation scheme in the CCAR's *responsa* described above – between action – being done – and inaction – action refrained from being done (2006, p. 86). In the same manner, Kravitz goes on interpreting the account of the execution of Rabbi Hanina (1995, pp. 14–15; 2006, pp. 80–82). He argues that this source is often incorrectly interpreted as opposing euthanasia and accepting withholding/withdrawing of life-sustaining treatment, on the basis of Rabbi Hanina's utterance "it's better that He who gave me my soul should take it and let no one harm himself", while at the same time asking the executioner to remove the wet tufts of wool. Rejecting this wrong interpretation, Kravitz asserts that Rabbi Hanina, faced by death and experiencing terrible pain, changes his mind and facilitates his own death. For, in the opinion of Kravitz, the conversation between Rabbi Hanina and the executioner has the character of a contract.

> The executioner said to him, "Rabbi, if I raise the flame and take away the tufts of wool from over thy heart, will thou cause me to enter into the life to come?" "Yes," he replied. "Then swear unto me" [he urged]. He swore unto him. He thereupon raised the flame and removed the tufts of wool from over his heart, and his soul departed speedily. *(Bavli Avodah Zarah 18a)*

"That the executioner asked rabbi Haninah to swear to his answer indicates that both executioner and rabbi knew what was to be the outcome and what was to be the consideration, the quid pro quo" (2006, p. 81). Moreover, as Knobel indicates, the story tells that the executioner is granted immediate eternal life for his act of mercy: "In fact one can read this passage to suggest that relief of suffering which hastens death is not only permitted but meritorious, so meritorious that the executioner is immediately ushered into internal life" (1995, p. 43).

The rejection of the difference between euthanasia (considered as action) and withdrawing/withholding life-sustaining treatment (considered as inaction) is also applied to *Bavli Ketubot* 104a. According to both Reform Rabbis Kravitz (1995, pp. 15–16; 2006, pp. 82–83) and Knobel (1995, p. 44), the physical act of the maid – throwing down the pot from the roof and as a result startling the rabbis and disrupting their prayers – caused Rabbi Judah to die. Moreover, Knobel asserts that she killed him – out of compassion. Rabbi Judah did not die as a result of 'indirect action', but "the maid's act clearly terminated his life" (Knobel 1995, p. 44). Kravitz (1995, p. 14) holds the same view: "She interfered with Rabbi's life support system. She acted; he died. One may say that she enabled him to die or one may say that she caused him to die; in either case, her act precipitated his death".

Apart from these sources both rabbis refer to the fact that euthanasia, literally meaning 'good or easy death' has its parallel Hebrew term in the Talmud, namely '***mitah yafah***', meaning "a nice death" (Kravitz 1995, p. 21; 2006, pp. 78–79; Knobel 1995, pp. 45–46). This term is found in the Talmudic tractate *Sanhedrin* 52a in the context of a discussion of a judicial execution. The Talmud tells us that for the condemned criminal we should choose a nice death, i.e. a quick, non-humiliating death. "If we are to view condemned criminals as our neighbors and compassionately provide them with a rapid and non-humiliating death, what, then, is our obligation to innocent life which is suffering terrible pain and humiliating death?" (Knobel 1995, p. 46).

Based on these considerations of the mentioned sources, both Reform rabbis assert that the preservation of life is valued by the Jewish tradition as an important ***mitzvah***, but biological life is not a supreme value which overrides all other considerations. According to Kravitz (1995, p. 21) euthanasia is only an option in case of someone who is in the process of dying and who suffers unbearably. Knobel asserts that in extreme situations the termination of human life is not a sin, but can in fact be praiseworthy. For him, "the determining factor is whether the termination of life is consistent with the preservation of the person as being created ***b'tzelem elohim*** (in God's image). In other words, does the continuation of biological life violate the sacred character of the individual's life? Therefore, the aggadah, the sacred narrative of a person's life, becomes part of the halakhic decision-making process" (Knobel 1995, p. 48).

We conclude this Reform pro-euthanasia view with the words of Kravitz: "Where pain trumps life, where suffering cannot be controlled and recovery cannot be achieved, then if the patient feels that life is no longer worth living, and 'the game not worth the candle', there is no need to extend life, and indeed, there may be a need to shorten it" (2006, 93).

4.7 Conclusions

Although human life is extremely precious for religious Jews, arguing that the Jewish tradition uniformly condemns euthanasia would do harm to one of the essential characteristics of Judaism: heterogeneity. After all, within Judaism and its diverse movements a central, coordinating Jewish authority that proclaims official Jewish statements is lacking. This Jewish plurality is reflected in the debate on ethical dilemmas, such as euthanasia.

Yet, in our review no advocates of euthanasia were found in the Orthodox movement. The overriding importance of preserving human life was illustrated by the sanctity of life approach of prominent American Rabbi Bleich. Similarly, other Orthodox

rabbinic authorities, such as Jakobovits (1959, p. 123), Feinstein (Tendler 1996, p. 60) and Tendler (1996, pp. 138, 142), oppose (active) euthanasia. Indeed, Tendler and Rosner argue that "Jewish law opposes euthanasia without qualification and it condemns as sheer murder any active or deliberate hastening of death, whether the physician acts with or without the patient's consent" (1993, p. 20; 1996, p. 138). Reviewing liberal Jewish opinions, intra-branch diversity was found. In the Conservative movement, while Rabbis Dorff and Reisner are both fierce opponents of euthanasia, we noticed Rabbi Sherwin's acceptance of euthanasia. In the same manner we recorded diversity of opinion in the Reform movement: while the Central Conference of American Rabbis holds to a prohibition of euthanasia, we found Rabbis Kravitz and Knobel as convinced supporters of it, referring to the same Jewish textual tradition. Without neglecting this inner-Jewish heterogeneity, it must be stressed, however, that pro-euthanasia opinions are exceptional voices, even within the Conservative and Reform branch of Judaism.

The fact that no advocates of euthanasia were found on the Orthodox side, is not very surprising, considering the fact that liberal Jews – Conservatives in a lesser degree than Reform Jews – consider the *halacha* as mainly the work of human hands, having an advisory function, and being open to recontextualization in the light of contemporary realities. In contrast, according to Orthodox Judaism *halacha* reveals God's will, which is definitive and essentially normative. Thus, the fact that divergent interpretations of the same sources are found is not accidentally, but reflects the essential pluralistic character of Jewish ethical reasoning (Ellenson 1995). The way in which rabbis perceive the (status of the) Jewish textual tradition and the manner in which they reflect on it and distill essential principles from the texts – in confrontation with a contemporary case – influence their statement on an ethical dilemma. Perceiving *halacha* as normative and binding or as guiding and advising affects rabbis' coping with and opinion on a (contemporary) ethical question. The authority rabbis ascribe to the Jewish textual tradition, as well as the interpretive process itself gives evidence of pluralism, which even exceeds 'denominational boundaries' (Ellenson 1995, p. 135).

Apart from this Jewish inter- and intra-branch heterogeneity the debate on euthanasia discloses as well a continuous element: the text-centeredness of Jewish ethics. Indeed, ethical reasoning is based on the corpus of Jewish law, which consists of Torah and the tradition of rabbinic interpretation. Although rabbis and movements ascribe diverging degrees of authority to (interpretations of) *halacha*, our analysis shows that it is never completely excluded or dismissed. Though we made mention of an antinomist position in Reform Judaism (Jacob 2004), ethical reasoning in Judaism predominantly presupposes reference to the Jewish textual tradition (Zoloth-Dorfman 1995) thus is – exclusively or not exclusively – *halachic*.

When caring for Jewish patients, for healthcare professionals it is essential to be aware of the influence of the Jewish (textual) heritage on concrete medical decisions. After all, religious Jews' daily life choices (must) fit in with God's path. As they wish to follow God's example (*imitatio Dei*) (Shapiro 1978, pp. 127–151; Mackler 2003, p. 6) rabbis and *poskim* (experts of Jewish law) are central authorities for them. Indeed, in virtually all aspects of life – for instance regarding medical decision making – the influential role of rabbis may not be underestimated. After all, rabbis' casuistic reasoning typifies Jewish ethics. In this way, a concrete rabbinic decision on a given case may differ from abstract, theoretical *halachic* considerations. Especially among Orthodox Jews, rabbinic involvement in and rabbis' (binding) advice on everyday life and moral conduct, might appear in healthcare settings (Coleman-Brueckheimer, Spitzer & Koffman 2009). Nurses and physicians might not be familiar with this. Showing understanding for this (possibly) influential role of rabbis, is part of showing respect for a patient's autonomy. Throughout the different branches of Judaism, the role of rabbis is variously perceived. While Orthodox rabbis' decisions are assumed to be binding, *responsa* of liberal rabbis are ascribed a rather guiding and advising character. Although Judaism's movements can be distinguished by characteristic tendencies, they are hardly monolithic. Therefore, when dealing with Jewish patients, it is not only essential to be acquainted with Judaism's diverse branches, exposing the essential Jewish heterogeneity, but as well with a patient's specific religious context.

As mentioned previously, Jewish voices in favor of (active) euthanasia are rather exceptional and uncommon (Gesundheit *et al.* 2006). Indeed, emphasis on the supreme value of human life and thus on its preservation is central in Judaism (Jakobovits 1959; Tendler & Rosner 1993; Glick 1999; Rosner 1986a; 1986b; 1999; Freedman 1999). Tendler and Rosner even mention a "unanimity of halakhic opinion that active euthanasia is never condoned" (1993, p. 23; 1996, p. 142). Likewise, the CCAR mentions the "unequivocal voice of the halachic literature" (Plaut & Washofsky 1997, p. 340) in this matter. For healthcare professionals it is important to take the delicacy of this issue for Jews and their hesitance toward quality of life judgments (Schostak 1991; Mackler 2003, p. 108; Zohar 2006, p. 2) into account. On the other hand, among contemporary (Jewish) academic scholars the prevailing Jewish emphasis on life-saving is challenged and debate on the significance of improving a patient's quality of life is stimulated (Brody 1999; Green 1999; Zohar 2006). Brody and Green for instance argue that the idea that Judaism is committed to the strict doctrine of sanctity of life is a thorough misrepresentation and does not do justice to the nuanced way of thinking of rabbinic casuistry. Orthodox authorities acknowledge that Judaism is concerned about a patient's pain and suffering, thus his/her quality of life (Tendler & Rosner 1993; Tendler 1996), yet determining "whether life is

worth living" (Rosner 1991, p. 44) on the basis of quality of life considerations is for them a bridge too far.

Anyway, it is utmost important to provide care which is sensitive to a patient's religion, world view and culture. The huge importance of culture-sensitive care, which evidently entails respect for a patient's autonomy, is demonstrated by the reflections of Jotkowitz, Glick and Zivotofsky (2010a; 2010b) and Gesundheit (2010) on the Canadian Golubchuk case. They point correctly to the importance of training of healthcare professionals "in communication skills and cross-cultural medicine" (Jotkowitz, Glick & Zovotofsky 2010b), a requirement which is indispensable given the multicultural and multireligious outlook of contemporary societies. Indeed, religion and world view have influence on the way people deal with illness and ethical dilemmas, for instance in health care (Gielen, Van den Branden & Broeckaert 2009a; Coleman, Koffman & Daniels 2007; Wenger & Carmel 2004; DeKeyser Ganz & Musgrave 2006; Margalith, Musgrave & Goldschmidt 2003; Musgrave, Margalith & Goldsmidt 2001; Ejaz 2000; Leichtentritt & Rettig 1999; Carmel & Mutran 1997). Consequently, hospitals' need felt to deal with a culturally diverse patient population is high, which is clear from the steady inquiries to our center[1] to provide training and clear guidelines in this regard. Nowadays, a holistic approach of patients, paying attention to their (cultural) background and religious convictions, which may impact considerably on medical decision making, is utmost appropriate, as it undoubtedly contributes to providing optimal care.

[1] Interdisciplinary Centre for the Study of Religion and World View (Catholic University Leuven, Belgium). Website: http://theo.kuleuven.be/page/icsrw

5 Orthodox Jewish Perspectives on Withholding and Withdrawing Life-Sustaining Treatment

5.1 Introduction

The central question that comes forward when discussing choices with regard to curative and life-sustaining treatment is: when does our duty to heal come to an end and when is it permitted to leave nature to its own devices? This question arises more strongly in our contemporary advanced medical context. The 'miracles' of modern medicine have turned death into a problem. Now, medical technologies create the possibility for patients to balance – even for a very long time – on the dividing line between life and death. As a consequence, health care increasingly entails difficult ethical dilemmas.

The way people deal with illness and ethical dilemmas in health care is in an important way influenced by religion or world view. This is also clear from several empirical studies conducted among (Jewish) medical practitioners (Gielen, Van den Branden & Broeckaert 2009a; Wenger & Carmel 2004; DeKeyser Ganz & Musgrave 2006; Musgrave, Margalith & Goldsmidt 2001; Margalith, Musgrave & Goldschmidt 2003) and (Jewish) patients and elderly (Coleman, Koffman & Daniels 2007; Ejaz 2000; Carmel & Mutran 1997; Leichtentritt & Rettig 1999; Baeke, Wils & Broeckaert 2011b). Thus, the importance of religion and world view in health care extends beyond merely spiritual care. Their significant influential role in concrete treatment decisions should be taken into account by contemporary clinical practice, particularly because it is all the more confronted with religious and cultural diversity. The need felt to cope with this plurality is high, which is for instance clear from hospitals' steady requests to our centre[1] for training and clear guidelines in this regard.

For the Jewish religious tradition the evolution in medical science raises urgent questions, given the Jewish emphasis on *pikuah nefesh* – the preservation of life. Does indeed in all circumstances life have to be preserved at all costs, or are there any exceptions and how is this justified according to the Jewish law? Though the article focuses on the perspectives of one branch of Judaism (the Orthodox movement) on withholding and withdrawing life-sustaining treatment, in the discussion section we briefly consider viewpoints on the matter of two religious liberal Jewish movements, Reform and Conservative. In this way the characteristic traits of Orthodox perspectives on the issue stand out.

Indeed, Jewish ethics are *halachic*, which means that these consist in providing an answer to a problem by addressing Jewish law (*halacha*) (Newman 1992; 2005). Sources of *halacha* are the Torah, the Talmud (consisting of Mishna – collection of the Oral Law – and Gemara – commentaries on the Mishna), the codes of Jewish law (for instance the Shulchan Aruch), and *teshuvot* or *responsa*, in which rabbis address actual dilemmas and cases from a *halachic* angle. Upon being confronted with an ethical dilemma individual Jews can ask rabbis for guidance (Mackler 2003), which they provide by relying on the aforementioned sources (Dorff & Newman 1995; Kellner 1995; Bollag 2006), taking at the same time the specific context of the case at hand into account. As such, a casuistic approach is characteristic for Jewish ethical reasoning (Steinberg 1994; Jakobovits 1997): relevant precedent cases in Talmudic and rabbinic sources are distilled and applied to the case at hand (Newman 1992).

This method of Jewish ethics can be defined as "casuistic deontology" (Zoloth-Dorfman 1995), being sensitive to case-specific contexts, while confronting these with analogical precedent cases, rules, values and principles found in the corpus of Jewish law. This "reflective equilibrium approach" (Mackler 1995; Jotkowitz 2010) or back-and-forth reasoning between specific cases, precedents and general principles is obvious in rabbinic *responsa*, which address individual Jews' urgent requests for ethical guidance in actual cases. When giving an overview of Orthodox Jewish perspectives on curative and life-sustaining treatment the casuistic character of Jewish ethics should be kept in mind. This means that, given the specific context of each case, decisions on similar ethical dilemmas may vary (Glick 1997) and theoretical *halachic* discussions may differ from real-life decisions (Kellner 1995).

5.2 THE *MITZVAH* OF PRESERVATION OF LIFE

Jews believe in a God who created human beings according to His image (Jacobs 1995). This condition gives human beings a unique position: they are granted the privilege to become God's partner in creation (Mackler 2003; Dorff 1998). At the same time this privilege also entails responsibility: as each human being is created in God's image, everyone has a unique and infinite worth (Dorff 1998; Rosner 1986a; Bleich 1993). Consequently, in Judaism all human lives are equal and they are not to be trifled with (Dorff 2003; Glick 1999; Mackler 2000). Judaism summons people to treat life and body respectfully. After all, humans are (only) stewards of their life and body; these are not their property, but they are on loan from God (Glick 1999). Life and body must be handled with extreme care and utmost reverence, in order to give it back to God intact at the moment God decides. Consequently, each Jew is summoned to respect the *mitzvah* – the precept –

of *pikuah nefesh*, preservation of life (Bleich 1979a). This is a central Jewish commandment, that takes precedence over all other religious regulations, except for the ban on the three cardinal sins: idolatry, murder and perverse sexual behaviour (Glick 1999; Bleich 1979c; Rosner 1999; Freedman 1999). Violating Jewish law in order to save life is not only permitted, it is mandatory (Dorff 2003; Glick 1999; Rosner 1984; 1986a). Human beings are summoned to protect, preserve and save human life, wherever possible. Therefore, Jewish views in favour of (active) euthanasia are very exceptional. Indeed, Judaism (almost) categorically excludes (active) euthanasia (Gesundheit *et al.* 2006; Baeke, Wils & Broeckaert 2011a).

5.3 THE *HALACHIC* STATE OF THE MORIBUND

Due to the sanctity of life and the *mitzvah* of preservation of life, the interaction with a dying person is carefully stipulated in Jewish law. A moribund person is called 'a *goses*'. Jewish law presumes that a person in the state of *gesisah* (being a *goses*) will die within 72 hours or three days (Jakobovits 1975; Bleich 1996; Sinclair 2003). He/she is recognizable by his/her difficulty to breathe and the death rattle. A *goses* is someone whose time to die has come, as a result of illness or old age. In his/her last moments of life he/she has to be treated according to his/her living status (Jakobovits 1975; Sinclair 1989; 2003), as it is noted in tractate *Semahot*, one of the later tractates of the Babylonian Talmud on dying, burial and mourning:

> A dying man is considered the same as a living man in every respect [...] His jaws may not be bound, nor his orifices stopped, and no metal vessel or any other cooling object may be placed upon his belly until the moment he dies, as it is written, Before the silver cord is snapped asunder, and the golden bowl shattered, and the pitcher is broken at the fountain (Eccl. 12:6). He may not be stirred, nor may he be washed, and he should not be laid upon sand or salt, until he dies. His eyes may not be closed. Whosever touches him or stirs him sheds blood. Rabbi Meir used to compare a dying man to a flickering lamp: the moment one touches it he puts it out. So, too, whosever closes the eyes of a dying man is accounted as though he has snuffed out his life. There may be no rending of clothes, no baring of shoulders, nor eulogizing, and no coffin may be brought into the house, until the moment he dies (Zlotnick 1966).

From this quote we learn that it is inappropriate to act as if the *goses* is already dead. Moreover, we are warned to treat the *goses* cautiously: he/she should not be moved or

touched, since this could speed up the dying process (Jakobovits 1975; Sinclair 2003). In this case one would be guilty of shedding blood. On the other hand, the 13th century *Sefer Hasidim* ('book of the Pious'), an influential ethical work developed by the medieval German *Hasidei Ashkenaz* movement, states that the departing of the soul from the body may not be hindered as well. Hindrances for the death of a *goses* may be removed.

> If the person is dying and someone near the house is chopping wood so that the soul cannot depart then one should remove the (wood)chopper from there (Rosner & Bleich 1979).

Thus, while Judaism emphasizes the preciousness of human life – death may not be hastened – it states as well that the process of dying may not be stretched. Thus, a distinction is made between precipitating death and removing an impediment (Sinclair 1989; 2003). This is also clear from the glosses on the Shulchan Aruch – the authoritative code of Jewish law – of the famous 16th century codifier Moses Isserles:

> It is forbidden to cause the dying to die quickly, such as one who is moribund (goses) over a long time and who cannot die, it is forbidden to remove the pillow from under him on the assumption that certain birdfeathers prevent his death. So too one may not move him from his place. Similarly, one can not place the keys of the synagogue beneath his head [on the assumption that their presence hastens death], or move him so that he may die. But if there is something that delays his death, such as a nearby woodchopper making a noise, or there is salt on his tongue, and these prevent his speedy death, one can remove them, for this does not involve any action at all, but the removal of the preventive agent (*Yore Deah* 339:1, quoted in Newman 1995b).

5.4 Orthodox Jewish perspectives on withholding/withdrawing life-sustaining treatment

In Judaism there is no coordinating authority that proclaims official statements regarding among others bioethical issues. Rather, individual scholars of Jewish law and rabbis hold their view on ethical dilemmas and specific cases, based on an interpretation of traditional Jewish sources, such as the ones discussed earlier. The weight given to a *responsum* depends on different factors, such as the reputation and status of the *halachic* expert or rabbi (Bollag 2006; Flancbaum 2001). As such, consensus opinions in the (Orthodox) Jewish community are usually based on the rulings of particular prominent

experts of Jewish law, such as the late Rabbi Moshe Feinstein (1895-1986). Rabbi J David Bleich too is considered a rabbinic authority on Jewish law and (biomedical) ethics. Both published extensively on the application of *halacha* to contemporary medical innovation and its ethical dilemmas.

Throughout his publications Orthodox Rabbi J David Bleich emphasizes the sanctity of human life (Bleich 1993). Moreover, he stresses not only the preciousness of human life, but also the inestimable and infinite value of every single moment of life. He refers to the *halachic* passage (Babylonian Talmud *Yoma* 84b–85a) that Sabbath must be violated in order to free someone who is buried under the rubble of a collapsed building, even if it is probable that he/she is in such a condition that his/her life could only be prolonged for a very short time after he/she is freed (Bleich 1996; 2006). To enforce his stress on the sanctity of life, Bleich (1996; 2006) explicitly refers to the Jewish faith that humans are not the owners of their lives and bodies – God is. Consequently, a human being cannot claim absolute autonomy. As persons do not have the right to judge a human being's quality of life, since this life has an intrinsic value, they are obligated to consistently follow the *mitzvah* (commandment) of *pikuah nefesh* (preservation of life).

In Bleich's opinion, this duty to save and preserve life is absolute and unconditional – irrespective of the physical and mental health of a person – thus may not depend on the quality of life which is preserved: "Judaism denies man the right to make judgments with regard to quality of life [...] the *mitzvah* of saving a life is neither enhanced nor diminished by virtue of the quality of life preserved" (Bleich 1996; 1979a; 1978) Whoever does this, and withholds or withdraws curative or life-sustaining treatment for this reason, is, according to Bleich (2006; 2010), guilty of homicide. For the same reason, Bleich (1996) denounces the use of a living will. For Bleich (1996), personal autonomy "is a paramount value ***when it does not conflict with other divinely established values***" [italics ours].

Even from an incurable patient medical resources may not be withheld. Moreover, Bleich makes no distinction between natural and artificial means of treatment: God made food and water, as well as medication and technology available to humans. Thus, human beings are obliged to use them to ward off illness and to prolong life (Bleich 1996). For Bleich, dutifully swallowing prescribed medication is not in contradiction with praying to God not to prolong life. "The ultimate decision, however, is God's, and God's alone" (Bleich 1996; 1978). Although stating that the distinction between ordinary and extra-ordinary means of treatment has no parallel in Jewish sources, Bleich (1996; 2006; 1978) acknowledges that human beings are not obliged to undergo experimental treatments and therapies which are hazardous in nature.

Withholding treatment – Bleich (1996; 2006) uses the term "passive euthanasia" – is allowed only in the case of a moribund person (*goses*). "The distinction between an active

and a passive act [...] applies to a *goses* and to a *goses* only" (Bleich 1996). Bleich's definition of a *goses* runs parallel to the description in *halacha*: a *goses* is a patient whose death is imminent, whose breathing is laboured, who brings up secretion in his/her throat and who is expected to die within three days or 72 hours. Yet, Bleich (1996) adds that a *goses* in Talmudic times differs from a *goses* in our contemporary context, taking into account the advances in medicine. For Bleich (1979c) in our current context a *goses* is "one who cannot, under any circumstances, be maintained alive for a period of seventy-two hours". This means that his/her state is "not only irreversible but also not prolongable even by artificial means" (Bleich 1979c). Thus, if it is medically feasible to hinder the dying process from setting in, to restore the *goses* to good health or to reverse the state of being moribund, every possible medical measure should be taken. At the same time Bleich seems to limit the interventions which may be forgone in the case of a *goses* to folk remedies or remedies of undemonstrated efficacy – referring to the salt on the tongue of a patient and the noise of a woodchopper in the Jewish textual sources. Thus, "normal forms of life-prolonging therapy must be administered to a *goses* just as they are administered to any other patient" (Bleich 1996).

In Bleich's opinion, in the case of terminal patients with a longer life expectancy physicians may not abandon their responsibility to prolong life. "The terminal nature of an illness in no way mitigates the physician's responsibilities, because the physician is charged with prolonging life no less than with effecting a cure" (Bleich 1996; 2006). Everything has to be done in order to postpone the process of dying from setting in. Only when unbearable pain cannot be treated, Bleich would admit to withhold life-sustaining treatment (Bleich 1996). Nevertheless, Bleich (2006) is convinced of the fact that physical suffering in most cases can be treated adequately, provided that physicians are better trained in this regard. For Bleich, the obligation to maintain life-sustaining treatment is almost absolute.

In contrast with Rabbi Bleich the late Rabbi Moshe Feinstein does not restrict withholding life-sustaining treatment to *gosesim*. In his opinion, *halacha* justifies withholding treatment in two cases. First, in case of a *goses* medical interventions should not be administered, except for essential comfort care, "such as cleansing and providing liquids by mouth to overcome dryness" (Tendler 1996). In light of routine care offered to patients in intensive care units nowadays, Feinstein states that it is necessary to evaluate the *halacha* which forbids to have any physical contact with a *goses* (Tendler 1996). Indeed, in Jewish law a moribund person is likened to a sputtering wick, which should not be touched. For Feinstein, all supportive care – including nutrition and hydration —should be maintained, on condition that it is for the patient's benefit and does not cause unnecessary pain. Second, Feinstein argues that a physician is allowed to withhold treatment when there is no hope for a cure and when therapy only prolongs the untreatable agony of the patient. In his

response (Tendler 1996) Rabbi Feinstein states that a patient's quality of life does play a role in medical decision making. For Feinstein, a patient's untreatable suffering, even in the case of a terminally ill patient with a life expectancy of several weeks or months, sufficiently justifies the choice to withhold treatment. In this case, a patient's life expectancy is not significant. "The key concern is their quality of life" (Tendler 1996).

For his statement that life with suffering should not be prolonged, Feinstein appeals to *halacha*, specifically to the Talmudic story about the death of Rabbi Judah ha-Nasi, who lived in the latter half of the third and the early second century and who was the redactor of the Mishna. While the surrounding rabbis pray God to preserve his life, Rabbi Judah's maid – being aware of Rabbi's unbearable agony – prays for his death and eventually interrupts the life-sustaining prayers of the surrounding rabbis by throwing a pot from the roof to the ground.

> On the day when Rabbi died, the rabbis decreed a public fast and offered prayers for heavenly mercy [...] Rabbi's handmaid ascended the roof and prayed: 'The immortals desire Rabbi [to join them] and the mortals desire him [to remain with them]; may it be the will [of God] that the mortals may overpower the immortals.' When, however she saw how often he resorted to the privy, painfully taking off his *tefillin* and putting them on again, she prayed: 'May it be the will [of the Almighty] that the immortals may overpower the mortals.' As the rabbis incessantly continued their prayers for [heavenly] mercy she took a jar and threw it down from the roof to the ground. [For a moment,] they ceased praying, and the soul of Rabbi departed to its eternal rest. *(Ketubot 104a)*

From this story Feinstein concludes: "therefore, if the patient is terminally ill and in intractable pain, so that there is no hope of his surviving in a condition free of pain, but it is possible, through medical or technological methods, to prolong his life, then it is improper to do so. Rather, the patient should be made as comfortable as possible, and left without any further intervention" (Tendler 1996).

On the other hand, Rabbi Feinstein does not seem to allow *withdrawing* treatment in case of a terminally ill or moribund patient. Indeed, stressing the importance of acting for a patient's benefit, he warns for oxygen hunger, being "a very painful experience" (Tendler 1996) and he emphasizes the maintenance of (artificial) nutrition and hydration. Moreover, Feinstein expresses his fear that removal of a ventilator – for service or replacement of the oxygen tank – might cause a patient's death. If the patient appears to be still alive once the respirator is removed, he/she should be reconnected. In this way "there will be no chance

of contributing to his death or being negligent in his cure for even the slightest period of temporary life" (Tendler 1996; Feinstein 1987).

In case a patient refuses a treatment expected to benefit and cure him/her, Feinstein argues that this patient must be coerced – in close consultation with his/her family – even if the treatment might cause pain and discomfort. Yet, for Feinstein, this is not allowed in case of risky treatment, and coercion should not imply the use of physical force, as this may frighten, stress and depress the patient (Tendler 1996). In the same manner, "a patient should not be restrained physically in order to provide him with nutrition" (Tendler 1996). According to Feinstein, decisions should be taken in close consultation with family members and "the patient's opinion, in cases where there is doubt as to what is appropriate, must be given full authority" (Tendler 1996).

5.5 Discussion

Rabbi Bleich and Rabbi Feinstein are both adherents of Orthodox Judaism and refer to the same Jewish textual tradition when reflecting on ethical dilemmas. Despite this we hear divergent opinions with regard to the desirability of initiating life-sustaining treatment. Referring frequently to the *mitzvah* of *pikuah nefesh*, Bleich emphasizes the unconditional sanctity of life. For him, life must be prolonged at all costs, except in the case of a *goses*, and everything must be done to postpone the process of dying from setting in. While, according to him, human beings do not have the right to judge the quality of human life, quality of life is one of Feinstein's arguments that plays a role in his opinion on the matter. However, Feinstein does not deny the value of human life: like Bleich he emphasizes that actively terminating life is absolutely prohibited. All the same, Feinstein finds in *halacha*, apart from the emphasis on sanctity of life, also the importance of quality of life. Thus, for him treatment can not only be withheld in the case of a *goses*, but also in the case of a terminal patient who suffers unbearable pain and has a life expectancy of even several weeks or months. Despite this different accent, both authorities would admit to withhold life-sustaining treatment from a terminally ill patient in case suffering cannot be mitigated. According to Sinclair (2003) all modern authorities agree that a dying person "should be spared as much physical and mental suffering as possible". Nevertheless, from his utterance that life with suffering is preferable to death, (Bleich 1979c; 1996), it is clear that Bleich – to a greater extent than Feinstein – stresses the (absolute) necessity to treat (terminally ill) patients, unless there is persuasive reason not to.

Feinstein and Bleich both recognize the value of the *halachic* concept *goses* and use it as traditionally defined (yet, Feinstein does not restrict withholding to the case of a *goses*). Nevertheless, both rabbis express the need to evaluate the *halachic* concept of *goses* in light

of contemporary advances in medicine. For Feinstein it is difficult not to touch contemporary *gosesim*, as comfort care must be provided to dying patients. Recognizing the developments in contemporary medicine, Bleich, in his turn, specifies the *goses* definition: a *goses* is someone who is presumed to die within 72 hours *even with medical support*. Although Bleich wants to show in this way that he is prepared to take the changing medical context into account, Jewish bioethicist Ronald Green, one of his staunch critics, holds against him that in this way he actually propagates futile treatment, rather than taking the contemporary medical context seriously into consideration (Green 1985; 1999).

From their writings it is clear that Bleich and Feinstein do not permit *withdrawal* of life-support. Bleich condemns withdrawal of treatment (even in the case of a *goses*), referring to the famous Quinlan-case (Bleich 1979a; 1978). Expressing his fear to cause a patient's death upon removal of a ventilator, Rabbi Feinstein as well seems to make a distinction between withholding and withdrawing treatment. However, Jewish scholars and rabbis seem to be in disagreement with regard to the (moral) distinction between both. For some both are acts of omission, in which nature is allowed to take its course. For others, withdrawal of treatment is an act of commission, and thus problematic, as it is considered equal to active termination of life (Flancbaum 2001; Zemer 1999). According to Sinclair (2003), Rabbi David HaLevi expresses an exceptional view among modern (Orthodox) *halachic* authorities, considering life-support as an impediment which may be removed in the final state of life. In contrast to other accepted *poskim* (*halachic* deciders) he has no problem with equalling withdrawal of life-support, such as a respirator, to removal of an impediment to death (authorized by the Shulchan Aruch), such as salt on the tongue of the patient or a woodchopper. For him, the artificial respirator, in the same way as the salt and the woodchopper, unnecessarily prolongs the dying process (HaLevi 1987). In contrast, most modern (Orthodox) *halachic* authorities reject the analogy between salt/woodchoppers and respirators. They only tolerate the removal of the former, since these are impediments which lack empirically proven life-preserving qualities. Withdrawal of life-support, on the other hand, would be clear death precipitation.

In order to meet rabbinic objections to withdrawal of life-sustainment, the new Israeli law on the care of the terminally ill (2005), introduced the use of timers on respirators (Barilan 2004; 2007; Ravitsky 2005). By proposing timer-dependent ventilators discontinuing mechanical ventilation is transformed from an act of commission into an act of omission. According to Jewish law a person is only responsible for "an action he commits, but not for things that merely happen [...] inaction leaves responsibility in the hands ofGod" (Barilan 2004). According to Conservative Rabbi Mackler, in Conservative and Reform circles withdrawal of treatment is generally considered equivalent to withholding (Mackler 2003).

The positions of Orthodox rabbis Bleich and Feinstein with respect to withholding treatment represent influential viewpoints in however only one segment of Judaism. Judaism is a heterogeneous religious tradition, which is reflected on a structural and organizational level in its various branches grown throughout history. Today, Orthodox, Conservative and Reform Judaism are the largest movements. With regard to the role of life-sustaining treatment in end-of-life care, Conservative and Reform opinions may differ from the Orthodox viewpoints presented in this article. Especially in more liberal Jewish circles, the relevance of the *halachic* concept *goses* in a contemporary medical context is sometimes questioned.

In order to take current medical advances and possibilities into account, Conservative rabbis Reisner and Dorff prefer to redefine this concept. For Reisner (2000b) a *goses* is a person who is "imminently dying", this means who suffers from a terminal illness, irrespective of life prognosis. According to Conservative Rabbi Dorff (1998) a person only becomes a *goses* in the last hours or minutes of life. For him the Jewish legal category of *terefah* ("a person suffering from a fatal condition for which there is no cure known to medical science" (Sinclair 2003)) is more appropriate to deal with treatment decisions at the end of life. In this way, Conservative rabbis Reisner and Dorff do not use the concept *goses* in the same (traditional) way as Orthodox rabbis Bleich and Feinstein do.

By rejecting the traditional definition of *goses* the views of Dorff and Reisner on the conditions in which treatment can be withheld differ essentially from Bleich's viewpoint. Reisner (2000a; 2000c) would allow to withhold medication, nutrition and hydration when these are not considered beneficial. Dorff would permit withholding medication, including artificial hydration and nutrition, in the case of a patient suffering from a fatal, incurable condition – including a patient in a persistent vegetative state (Reisner 2000c; Dorff 2004). As Feinstein does not restrict withholding of treatment to a *goses*, as traditionally defined, and considers a patient's quality of life, the positions of Reisner and Dorff, which are both endorsed by the Conservative Movement's Committee on Jewish Law and Standards, bear resemblance to his view on the matter. Yet, more than Reisner and Dorff do, Feinstein stresses the importance of providing life-support, such as nutrition and hydration, to a (dying) terminal patient.

In the Reform Jewish branch, considerable room is left for the patient's (and his/her family's) individual decision making with respect to withholding (and withdrawing) treatment. It seems that in Reform *responsa* of the Central Conference of American Rabbis (CCAR s.d.; Plaut & Washofsky 1997) this ethical issue is discussed without elaborate considerations on the definition of *goses*. This stands in clear contrast with the mentioned Orthodox and Conservative debates on the matter. For the Reform Central Conference of American Rabbis the primary and decisive criterion to withhold (and withdraw) treatment

is therapeutic effectiveness. Only when there is a reasonable chance of success, action should be taken to save life. The point and essence of medicine is to heal, thus unbeneficial and ineffective therapy ceases to be medicine and must not be administered. In this sense, only therapeutic procedures, "contributing to the successful treatment of the disease" (CCAR s.d.) are required. In the same way, in Reform circles there is considerable debate on whether artificial nutrition and hydration are medical treatment. As such, there are dissenting views on the permissibility to withhold and withdraw artificial nutrition and hydration in the case of terminal and dying patients (Plaut & Washofsky 1997; CCAR s.d.)

It is obvious that this Reform viewpoint is at odds with Bleich's stress on the almost absolute preservation of life. In contrast, this position bears resemblance to the Conservative viewpoints, and even to Orthodox Rabbi Feinstein's position, who emphasizes the importance of benefiting a patient, thus taking his/her quality of life into account. Yet, at the same time, Feinstein is determined that life-support should not be removed. More than liberal Jewish viewpoints on the matter, Orthodox rabbis' opinions seem more cautious about withdrawal of treatment – being viewed as death precipitation – and withholding life-sustaining treatment, especially "routine treatments" (Mackler 2003) and "artificial life-support" (Sinclair 2003) (oxygen, nutrition and hydration). Most contemporary Orthodox authorities are of the opinion that "artificial life-support must be maintained until the establishment of death" (Sinclair 2003).

From this analysis it is clear that Jewish coping with ethical dilemmas in health care is essentially different from dominant Western secular outlooks on health care matters. In several European countries rather small Jewish communities are found. Belgium, for instance, houses an estimated 40,000–50,000 Jews, who mainly live in Brussels and Antwerp. An important part of them are religious Orthodox (Antwerp) and Reform Jews (Brussels). Meeting their health care needs supposes acquaintance with their specific religious and ethical views. In order to amass this knowledge, training is essential. At the same time, physicians and nurses should be aware of the essential diversity in one religious or ideological tradition. Judaism, for instance, has diverse religious branches and only a minority of the worldwide Jewish population is religious. Thus, when caring for (Jewish) patients, it is indispensable to enter into conversation with the individual patient and his/her family in order to acquaint oneself with their personal religious convictions and their viewpoints regarding the permissibility to withhold or withdraw treatment.

In codes of ethics for caregivers this need to approach patients as individuals and to respect their personal concerns and preferences is stressed. In the international code of ethics for nurses developed by the International Council of Nurses (ICN 2006) respect for the individual patient is central. This is also obvious in other ethical codes for nurses, for instance the national professional code for nurses and caregivers in the Netherlands

(Beroepsvereniging van zorgprofessionals 2007) and the ethical code for nurses and midwives developed by the Nursing and Midwifery Council (2010) in the UK. None of these codes take an explicit stand in matters of withholding and withdrawing (futile) treatment, but three elements which come forward in the codes are relevant to the discussion at hand. First, the codes make mention of the importance of obtaining informed consent of a patient when a treatment is initiated. The codes state that patients have the right to choose or refuse a treatment. When dealing with (Orthodox) Jewish patients healthcare professionals might be confronted with strong demands of treatment, seeing the (Orthodox) Jewish emphasis on the value of human life and given the tendency (within Orthodox Judaism) to equal withdrawal of treatment with death precipitation. Second, the codes acknowledge that (most often) the patient is surrounded by relatives and a broader community, who must be approached too as partners in health care if the patient wishes so. When treating religious Jews, caregivers must be aware of the fact that family and community members, for instance rabbis, might play an influential role in medical decision making. Yet, of course, as the codes indicate, caregivers must respect a patient's right to confidentiality. Third, the international, as well as the Dutch and UK codes of ethics for nurses give evidence of a holistic approach of patients, having physical, psychological, existential and spiritual concerns. Specifically, the ICN and Dutch codes make explicit reference to the values, customs and spiritual beliefs of the individual patient, his/her family and surrounding community which must be respected. Both codes explicitly plead for rendering health care which is sensitive to culture and world view. They make mention of the need for training in this regard and the Dutch code explicitly asks nurses to acquaint themselves with the values and norms, culture and world view of the patients for whom they care. However, contemporary healthcare professionals must realize that paying attention to a patient's ideological and religious identity extends beyond providing prayer facilities and food which respects specific religious dietary laws. They must recognize that the impact of a patient's (religious) values and norms is felt in concrete ethical dilemmas regarding treatment decisions. This is abundantly clear from the case of Samuel Golubchuk, a Canadian Orthodox Jew (Jotkowitz, Glick & Zovotofsky 2010a; 2010b; Gesundheit 2010). Being on life-support during the final months of his life, the hospital attempted to withdraw his mechanical ventilation and tube-feeding, an action which was vehemently opposed by his relatives, as they considered it contrary to their religious beliefs. Being the subject of great media attention, the case gave evidence of the need to approach patients with appropriate sensitivity to their culture and worldview. Jotkowitz, Glick and Zivotofsky (2010a) note that the caregivers were clearly not informed about the Jewish emphasis on the value of life and the important differentiation in Judaism between withholding and withdrawing life-support, and that they have tried to impose their own values on the patient and his family. As such, "formal training in communication skills and

cross cultural medicine is crucial in trying to prevent these difficulties between patients, families and physicians" (Jotkowitz, Glick & Zivotofsky 2010b).

5.6 CONCLUSION

Nurses and physicians should be aware of the fact that paying attention to the religious dimension of a patient's identity is not restricted to offering spiritual care. They must acknowledge that religion and world view are important influential factors when a patient is confronted with a concrete bioethical dilemma. Jewish views on the permissibility of withholding/withdrawing life-sustaining treatment are rather diversified. Disparities in opinion are not only found between rabbis and adherents of different Jewish denominations. In fact, differences of opinion occur in one single Jewish movement as well. Our analysis of the viewpoints regarding withholding/withdrawing of life-sustaining treatment of two prominent Orthodox authorities in the area of Jewish medical ethics – Rabbi J David Bleich and the late Rabbi Moshe Feinstein – shows their divergent opinion. Nonetheless, the ethical reasoning of both is *halachic*, basing their views on concepts from Jewish law, such as *goses*. Moreover, both rabbis are very reticent about withdrawing life-sustainment and stipulate careful conditions with regard to withholding treatment. Basic life-support (oxygen, nutrition and hydration) is considered of utmost importance. Though *halachic* concepts are also taken into consideration by liberal (Conservative and Reform) rabbis, they often reach divergent conclusions.

Despite this fundamental heterogeneity in Jewish medical ethics, two general trends can be distinguished. First, Judaism recognizes human beings' autonomy and responsibility, while stressing simultaneously divine sovereignty. As such, rabbis and Jewish ethicists recognize "some range of autonomous choice" (Mackler 2003), but they oppose an unbridled right to self-determination. Second, given that Judaism highlights the value of human life and the imperative to preserve it, quality of life judgments are rather uncommon: "virtually all Jewish ethicists are hesitant to make judgments with regard to a patient's quality of life" (Mackler 2003). Indeed, although Feinstein refers to "quality of life" in his responsa, he expresses caution and states clearly that this concept may not be used in a sense which "would exclude those who have mental or physical disabilities" (Tendler 1996). Thus, virtually all Jewish authorities agree that a decision to forgo treatment can only be based on its effectiveness and not on whether life appears worthwhile or on one's unbridled autonomy over body, life and death. Obviously, when caring for Jewish patients, nurses and physicians should be aware of this cautious attitude.

When reviewing rabbis' opinions on an ethical dilemma, the casuistic nature of Jewish (medical) ethics has to be kept in mind. In the end, (often) patients' ethical

questions are considered on a case-by-case basis by competent rabbinic deciders, looking for analogical precedent cases in Talmudic and rabbinic literature. Consequently, abstract, theoretical *halachic* discussions may differ from concrete, real-life rabbinic decisions. When caring for Jewish patients, for nurses it is important to take this potential rabbinic involvement in ethical decision making in health care into account (Coleman-Brueckheimer, Spitzer & Koffman 2009). The role of rabbis in religious, especially Orthodox, Jews' lives and their everyday, for instance bioethical, decisions may not be underestimated. Indeed, their advice on everyday conduct and moral behaviour is often considered binding (Coleman-Brueckheimer, Spitzer & Koffman 2009). Nurses and other healthcare professionals might not be familiar with this. Then, respecting a patient's autonomy implies showing understanding for the (possibly) central role of rabbinic authorities in a patient's handling of ethical dilemmas. Indeed, as the mentioned codes of ethics for nurses stress, caregivers must acknowledge and respect that relatives and community members may become partners in health care if the patient wishes so. Additionally, physicians and nurses must be aware of the essential heterogeneity in Judaism, having diverse (religious) branches. Therefore – as the codes of ethics for nurses emphasize – acquaintance with individual (Jewish) patients' context, religious convictions and ethical views is of utmost importance.

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6 "For our own good". Jewish Views on Medicine and Illness

6.1 Introduction

During the last decennia biomedical technology has developed significantly. The power of humankind within the domain of life and death has increased drastically. Making use of available biomedical technology man is not only able to control and cure diseases, but in an important way he has gained the – almost divine – power to regulate his own life project, even his own death. Seeing that medicine does not deal with insensitive, impersonal robots but with animated persons, who are situated in a specific context, this medical revolution bumps into ethical questions. As situated beings, humans are adherents of a specific world view. This world view – their conception of life, of humankind, and of a transcendental reality – influences opinions on what ought to be done when they are confronted with questions of life and death. In other words, the way everything *is* according to us, as contextual beings, influences our opinions on what *ought* to be (Newman 2005, pp. 18-19; Gielen, Van den Branden & Broeckaert 2009a) and the meanings we construct of illness and health (Yehya & Dutta 2010). Especially for adherents to a theistic world view burning ethical challenges come forward and they are urged to tackle the relationship between religion and medical science.

In Western debate the relationship between religion and science and ethical debates in this respect are often approached from the point of view of the dominant Western ideological traditions, the Christian tradition and the non-religious humanist tradition (Cuttini et al. 2004; Gielen, Van den Branden & Broeckaert 2009a; Müller-Busch *et al.* 2004; Rurup *et al.* 2006; Ryynänen *et al.* 2002; Sorbye, Sorbye & Sorbye 1995; Sprung *et al.* 2003; 2007a; 2007b), while the voices of religious minorities – for instance Jews – remain often absent. Nevertheless, it is clear that this debate has a multicultural and multireligious character, given that it leaves nobody untouched and challenges everyone, irrespective of worldview. All the same, a lot of literature has been written on contemporary biomedical advances from a Jewish perspectives (e.g. Bleich 1981; Bleich & Rosner 1979; Dorff 1998; Mackler 2000; Rosner 1986a; Sherwin 1990; 2000; Sinclair 2003). However, empirical studies in this respect are lacking.

The objective of this article is to present (religious) Jewish perceptions of medicine and illness. As such this article reports of one aspect of an explorative qualitative empirical research among elderly (age 60-75) Jewish women in Antwerp, Belgium, investigating their perception of religion, illness and death and their attitudes toward treatment decisions at the end of life. The participants' perceptions are outlined against the backdrop of Jewish

theological convictions with regard to creation, God and humankind, and present-day rabbinical views on medicine and illness.

6.2 "GOD SAID, 'LET US MAKE MAN IN OUR IMAGE, AFTER OUR LIKENESS'"

Traditionally Jews have faith in a Creator-God, who has created human beings in His image (Jacobs 1995, p. 265; 2005, pp. 218-219). This God-created condition implies that each human life is unique and has an intrinsic worth (Dorff 2003, pp. 378-379; Mackler 2003, p. 3). Consequently, in Judaism all human life is equal (Dorff 1998, pp. 18-20; Glick 1999; Jacob 1995b; 1998). Lives of young persons do not have more value than elderly people's lives. A disabled person has to be treated with as much respect as one who is not disabled (Rosner 1986a, pp. 12, 35). Every human being possesses an irreplaceable dignity.

All this summons human beings to take responsibility in God's creation: they not only shoulder responsibility for the world, they are also stewards of their lives and bodies (Glick 1999, p. 46). Jewish law warns human beings not to trifle with their life and body given that these are not their property, but these are (conditionally) on loan from God and are to be treated with extreme care and utmost reverence (Dorff 1998, pp. 15-20; 2003, p. 378). Consequently, each Jew is summoned to observe the *mitzvah* (religious commandment) of *pikuah nefesh* (preservation of human life), which is a central Jewish commandment, that takes precedence over all other religious regulations, except for the ban on the three cardinal sins, idolatry, murder and forbidden sexual behaviour (Glick 1999, p. 45; Bleich 1979c, p. 19; Freedman 1999, p. 143; Rosner 1999, p. 99). Violating Jewish law to save life is not only permitted, it is mandatory (Glick 1999; Mackler 2003, p.5; Rosner 1986a, p. 35; 1984, p. 114). Indeed, as stewards of God human beings are summoned to protect and save (every moment of) human life, wherever possible, as it is regarded as being exceedingly precious (Rosner 1986a, p. 35; Bleich 1993; 2010).

Being created in God's image, human beings acquire a privileged status. God's act of creation not only reveals God's omnipotence; it also clears the way for human freedom. Human beings become God's partner in creation (Dorff 1998, p. 29; Mackler 2003, p. 8). This special status with which they are endowed must not make them overconfident and haughty. Although being God's stewards, human beings ar not equal to God, because they are not almighty and eternal, but restricted and finite. This summons them to stand in God's service and to follow God's paths, in this way sanctifying life and hallowing God's name. Therefore, human beings are not allowed to trifle with human life, given that it is a divine gift that has to be taken care of (Thomasma 1999). Nevertheless, the fact that the

world and human lives are ultimately in God's hands, does not imply that human beings are powerless and have to adopt a resigned attitude.

6.3 Elderly Jewish women's views on medicine and illness

6.3.1 Methods

Given the delicacy and intimacy of the topic, interviews were preferred as method for data collection, allowing for in-depth conversation about feelings and thoughts in a confidential atmosphere. Semistructured in-depth interviews were conducted with a purposeful sample of elderly (age ≥60) Jewish women (n=23) in Antwerp (Belgium) concerning their attitudes toward medicine, illness, dying and ethical decision making in advanced disease. The number of Jews who belong to the Orthodox Jewish community of Antwerp is estimated between 15.000 and 20.000, among them Hasidic Orthodox Jews (approx. 25%) (Gutwirth 2004), non-Hasidic Orthodox Jews (approx. 40%), as well as secularized Orthodox Jews (approx. 35%). Secularized Orthodox Jews do not consider themselves Orthodox, although they are member of the Orthodox Jewish community of Antwerp. For them, being Jewish is mainly being part of a people and culture and has little or any religious significance. Attending and participating in Jewish festivals and rituals (for instance circumcision, religious marriage, burial, Jewish New Year and so forth) is interpreted as being part of and handing on tradition.

Given the closeness of the Antwerp Orthodox Jewish community and the sensitive nature of the research topic, snowball sampling was applied in all groups. Women, aged between 60 and 75, were interviewed in their home following Grounded Theory methodology (Glaser & Strauss 1967; Strauss & Corbin 1998). The interviews were conducted making use of a demographic questionnaire and a semistructured topic list on religion, ageing, medicine, health, illness, death and treatment decisions at the end of life. With the respondents' consent, the interviews were recorded. On average each interview took 99 minutes. Data collection continued until theoretical saturation was reached, i.e. when no new elements and insights came forward from further interviewing. Data collection and analysis were concurrent. After each interview had been conducted, it was transcribed verbatim and anonymized making use of pseudonyms. Next, the interview was codified and analyzed according to Grounded Theory methodology. By adding codes to the data and through constant comparisons, key concepts were identified in the interviews and categories were systematically generated and interrelated. Analyses were discussed by the authors on a regular basis. For the data analysis MAXQDA 2007 was used. Given that this artiele focuses on Jewish interpretations of medicine and illness, only these results are presented.

6.3.2 Findings

With regard to coping with medicine and illness, participants were asked whether they could make sense of disease and how they perceived God's and the physician's role in disease. From their story it was found that their perception of illness were related to their image of God. In this sense, important differences were found between the views of secularized Orthodox and Orthodox interviewees. While the majority of the secularized Orthodox Jewish respondents considered themselves as irreligious or indecisive about their religiousness, every Orthodox Jewish interviewee said to be religious or very religious. This – and their specific image of God – had consequences for the way they dealt with disease.

6.3.2.1 Secularized Orthodox Jewish women

The majority of the eight secularized Orthodox Jewish women interviewed said to be irreligious or to doubt their religiousness. Only two respondents described themselves as religious. Nevertheless, all of them disagreed with the traditional Jewish creation theology, as described above. They were of the opinion that God does not play any role in disease. Obviously, seeing that they were denying or doubting God's existence, disease was for them merely a profane fact.

> Illness is an imbalance in the body which can be caused by a poor diet. It can be caused by making a wrong move or by the quality of the air we breath. […] And then, if there is something wrong I do not think about a punishment for this and that. No, I think it would be terrible if you. I shall give a terrible illustration: suppose that you have a child and something happens to it, and then you have the idea that you are punished for something. This is unlivable. […] I cannot believe that there is something, that there is a G, if you will, God, who might be there and who has created human beings who have so much evil in them. So, if we are created in God's image, then God is not good enough to fall down on your knees for him, to pray for him. That is my personal. If you look at the wars, if you look at the religious wars, if you look at the terror in the world, then I cannot have faith in a God. And should he be there, then it is not the kind of God for whom I should be entranced. So I am not able to, personally. That is impossible for me. (Ruth)

For Lisa and Arielle as well the evil in the world – and particularly the Shoah – made them doubt God's existence. This was also the case for Nicole who referred to disappointments in her own life. She reported that for her it is impossible to have faith. According to Joanna a religious person lacks logic. She considered herself as a strong person who does not need religion to hold on to.

Although they considered themselves religious (but not Orthodox), Leah and Josephine too interpreted illness on a profane level. Leah said to have faith in a good God who is powerless when it comes to the evil in the world.

> And I cannot bear the idea that they say that God has not done anything during the war. I think God could not do anything about the German army, about the mentality of Hitler. He could not do anything about it. What could God do in Bombay recently? Tell me that. Take away the guns and throw them away? No, he. No, he. What could he do? [...] They'll say: 'OK, it's God'. But, God, do not tell me that this is God's will that all those people have died. God does not want that. That's, that is not possible, that is not possible. [...] God does not want evil. I am sure of that. God does not want that. I think sometimes he is also at a dead loss what to do. (Leah)

According to Josephine as well God cannot be blamed for illness. Although she felt connected to God, who she considered responsible for things that are beyond human control, according to her, illness only has a profane cause.

> We, human beings call it God, because we have no other words for it, I think. There are certain things that happen to me of which I say 'there are things I cannot manipulate'. [...] Illness is something that is built up, I think, out of stress, out of daily life. It is not because I fell that God has punished me, no, please, no. No, absolutely not, that poor soul has already enough to bear (laughs). (Josephine)

Thus, for these secularized Orthodox Jewish respondents God does not play any role in disease, given that for them God does not exist or is a good God who is not almighty, thus not responsible for everything that happens in the world.

6.3.2.2 Orthodox Jewish women

All of the fifteen Orthodox (Hasidic and non-Hasidic) Jewish interviewees considered themselves as religious Orthodox Jews, who follow God's laws. They reported to have faith in a Creator God, who has created the world and humankind, and thus they

fully agreed with the traditional Jewish creation theology, as described above. Nevertheless, two out of nine non-Hasidic respondents – who considered themselves "modern Orthodox" – did not believe that God governs everything. Esther and Norah were of the opinion that God is the creator and governor of the world. At the same time they emphasized humankind's significant contribution to creation. According to them God does not want illness.

> Human beings are also there. A human being often does evil things and euh. Death, yes. I do think so. […] My husband always says 'you can flee to the other side of the earth, but if God has decided that that's the moment, you can't do anything about it'. […] No, I know in our community, when we attend a burial of a young person, rabbis sometimes say to us: 'people, you have to behave better. That's why such a thing as this happens. That such a young person has died'. Or if a child dies for example, the rabbis say: 'people, this is your fault, you have to behave better'. I don't think that is right. Not at all. (Esther)

According to the other seven non-Hasidic Orthodox and the six Hasidic participants, when illness strikes man this comes from God, as part of God's meaningful plan with the world. According to these women God is the almighty creator of everything on earth, including disease and cure.

> I know that God governs the world and everything happens according to His will. […] First of all I actually know that God can help me. Of course, I go to the doctor, therefore doctors exist. But I know, if God does not want me to be cured, then I won't be. (Tzippa)

For them, physicians are only the instruments through which God acts. They stated that the only response to illness is having trust and faith in God while simultaneously seeking medical advice and cure. Indeed, for them, preserving human life – being God's possession – is of ultimate importance. Nevertheless, they reported that ultimately God is the only Author of illness and recovery, of life and death.

> It's in His hands. So, I have to pray for a good health or when there is a problem. God, I depend on what He wants, ultimately, not a doctor. I have seen it and I have heard it, I know, it is not in the hands, God can do more than a doctor, so… Ultimately I have to turn to Him. […] ultimately it's in His hands. […] Ultimately, it is not in their hands, again God stands above them. But they, euh, are the ones who have to help us. You cannot say 'I

> don't go to a doctor and God will, will euh, euh, bring me what I need'. (Sarah)

> Cure comes from God. The doctors are His assistants. That's the way we see it. Actually, the doctor was sent by God to help, but he does not know everything. God knows more. (Chanah)

Moreover, the respondents believed that illness is not meaningless, and that there is a reason why it occurs. According to some women this reason is hidden from human beings. Judith had no answer to the question whether God has any intention with causing illness. She wondered whether it is a personal or a collective punishment or whether it is a test, but finally she did not know. Also Tamar was doubtful about that. Anyway, she did not consider it as a punishment.

> Maybe there is, when He [God] causes illness, He wants us to think a bit, and to live a little bit better. [...] Maybe, but I cannot see it as a punishment. (Tamar)

According to Chanah, Nechama, Chaya, Suzannah, Miriam, Leyla and Danielle, only God knows why he causes illness. They said that human beings cannot judge this; they have to accept it.

> You can never know what's the purpose. Maybe you will notice it many years later 'ah, it was good that I was ill then'. (Chanah)

Although Suzannah and Miriam thought that God's purpose with illness is hidden, they added a few guesses: illness might be a test, an exhortation to repent or a purifying preparation to enter the hereafter, but not a punishment.

> We don't know. But the rabbis think that and we also think that this is a test, a test. Everyone is tested in his life. [...] No, never, not a punishment. Never, never, never, not a punishment. [...] They say that good people are even more tested than evil ones. Because these good people maybe pay in this world for that little thing they have done wrong. And then they are pure in the other world. Maybe, we think, these are opinions. But not sure. But certainly it is not a punishment. Never a punishment. (Miriam)

Tzippa, Elizabeth, Sarah and Devorah thought that disease is a test, that it encourages to think, to repent or that it purifies to enter the next world.

> And this I believe, that what God does, whether it is easy for me or not, and pleasant or not, in the end it is good for me. [...] But I am convinced that it [illness] is from God and this wakens us. We have to think 'what is happening here?'. [...] But he does not want evil for us. I am sure of that. [...] It is purification, purification, preparing us for, for above, for when Mashiah comes. (Devorah)

Anyway, according to these respondents illness is for your own good. Leyla and Danielle were also of this opinion: everything that comes from God – including illness – is good for us. They reported that this is beyond human comprehension; given that human beings do not know what is good for them – only God does – they cannot pass judgment on illness, they have to accept it.

> [...] human beings sometimes don't know what is good for them. But God knows what's good for them. That's why I trust Him, because when He gives me something, it is to do me good. About everything that happens we say 'gam zeh le-tov': 'that is also for the good'. A testing, it is for the good. When I loose something, it is for the good. It has its reason. I do not understand everything. (Leyla)

6.4 Discussion

6.4.1 Medicine: partnership with God

In contrast to the secularized Orthodox interviewees, the overwhelming majority of the Orthodox (Hasidic and non-Hasidic) Jewish sample agreed with the traditional Jewish creation theology, which reveals that human life possesses infinite worth and thus, has to be saved and preserved (Rosner 1999). The enormous value of human life also implies that one may not expose oneself to danger; one must take care of one's body (Dorff 2003; Sherwin 1990; Eisenberg 2007). Where illness threatens life man is urged to turn to medicine to seek recovery (Dorff 1998, pp. 26-28; Rosner 1986a, pp. 15-21; 1999, pp. 99-105; Jakobovits 1975, pp. 6, 50; Isaacs 1998). In such a way, the strong emphasis in Jewish creation theology on the divine sovereignty does not imply that the Jewish tradition is suspicious of new medical technologies and scientific progress. On the contrary, Judaism gives man, who is partner in God's creation, the freedom to make (positive) use of nature to prevent and treat disease. As such the God-given nature is considered to be "the physician's tool to be employed in the art of healing" (Sherwin 1990, p. 71).

In our qualitative empirical research, the overwhelming majority of the Orthodox Jewish (Hasidic and non-Hasidic) interviewees fully endorsed that God's sovereignty and man's freedom in creation go hand in hand. Although illness is seen "as part of the divine scheme" human medical intervention "as interference with the deliberate design of providence" (Bleich 1981, pp. 1-2; 1979c, p. 20) constitutes no problem, because man has been given the divine license to heal, as an expression of *imitatio Dei* (Sherwin 1990, p. 70). This license is found in *Exodus* 21:18-19 (Bleich 1979c, p. 21; Rosner 1986a, p. 9; Sherwin 1990, p. 72, Rosner 2001, p. 7; Sinclair 2003; p. 145):

> If men quarrel and one strikes the other with a stone, or with his fist, and he doesn't die, but is confined to bed; if he rises again and walks around with his staff, then he who struck him shall be cleared; only he shall pay for the loss of his time, and shall provide for his healing until he is thoroughly healed.

From this verse the Talmud concludes that man has been given divine permission to heal: "on this basis a physician is granted the right to heal a patient" (*Bavli Baba Qamma* 85a). Nevertheless, the Tenach (*2 Chronicles* 16:12) also tells the story of king Asa, who is reprimanded because of consulting a doctor in illness instead of dedicating himself to God in prayer (Freedman 1999, p. 142). Indeed, throughout Jewish history physicians' license to heal has been questioned (Sherwin 1990; pp. 66-84; Rosner 2001, pp. 5-11). Reconciliation of God's omnipotence and man's interference was subject of intensive debate during ages, especially among medieval Jewish scholars, such as Nahmanides and Maimonides (Sinclair 2003, pp. 145-159; Zohar 1995, pp. 387-402).

Orthodox Jewish participants in our study were aware of this theological ambivalence, stressing God's providence and simultaneously humankind's freedom to act in God's creation. Indeed, the Babylonian Talmud talks about the *permission* to heal. According to Sinclair (2003, p. 146) "the use of the word 'permission' indicates that the virtue of human healing is not self-evident", as is also clear from the negative Talmudic remark: "The best among physicians is going to Gehenna" (*Bavli Qiddushin* 82a) (Rosner 1986a, pp. 37-43). According to Rabbi Olitzky (2000, p. 31), this quote is not aimed against medical practice, but wants to criticize those physicians who lose sight of their partnership with God – the spiritual side of their profession – and who give evidence of arrogance and excessive self-confidence. Sinclair (2003, p. 146) confirms Olitzky's reading of the verse as a possible additional interpretation, but for him "it also conveys the existence of reservations within Judaism regarding the desirability of human healing". Anyway, both interpretations indicate that rabbis – in response to suffering – recommend to balance human medicine and divine dedication through prayer.

This balance was also stressed by the majority of the Orthodox Jewish interviewees in our empirical study: consulting a physician as a Jew is only legitimate when keeping in mind that God is the only true healer and that the physician is only His instrument. According to Sinclair (2003, p. 147) this complementing perspective that takes into account the spiritual as well as the profane sphere "has become the standard response in Jewish theology to the issue of human healing". Indeed, *Exodus* 15:26 indicates that God is the One who heals, while *Sirach* 38 states that a (worldly) physician – as "instrument of Providence" (Rosner 1986a, p. 20; 2001, p. 18) – deserves great honor.

Jewish faith in partnership with God does not only raise the question of medical science's *legitimacy*, but also of the *duty* of a sick person to consult a doctor and the latter's *duty* to heal. In the Orthodox Jewish sample of our study, both dimensions – medicine's legitimacy and the obligation to seek healing – clearly came forward. Most Orthodox participants in our study concurred with the Jewish religious conviction that God is giver and taker of life and that human beings' lives and bodies are a temporary gift from God, which reveals the human responsibility to deal with it carefully as God's stewards. In rabbinic circles *Exodus* 21:18-20 is understood as giving a physician the *permission* to cure, while *Deuteronomy* 22:2 ("and you shall restore it to him") "imposes the *obligation* to restore another person's body as well as his property, and hence to come to the aid of someone else in a life-threatening situation" (Dorff 1998, p. 27; Sherwin 1990, p. 72). Actually this Biblical verse refers to the scriptural commandment to restore lost property. According to Rosner (1986a, p. 10), Maimonides included in this commandment the obligation to restore a fellow's health. According to Orthodox Rabbi Bleich (1979c, p. 23) "dispensation to intervene in the natural order is derived from Exodus 21:20; but once such license is given, medical therapy is not simply elective but acquires the status of a positive obligation". Thus, in Judaism preserving and saving human life is a *halachic* (legal) commandment.

According to the Jewish physician Fred Rosner, there is a second scriptural mandate for the physician to heal: "you shall not stand idly by the blood of your neighbor" (*Leviticus* 19:16). Referring to this Biblical verse, tractate *Sanhedrin* (73a) of the Babylonian Talmud states that one has the duty to save a fellow who is in danger (Rosner 1986a, p. 11). Moreover, the Bible commands us to "love your neighbor as yourself" (*Leviticus* 19:18). On the basis of this the physician has the permission *and* the duty to heal. The mandate to seek healing is also emphasized by Judaism. A passage in tractate *Sanhedrin* of the Babylonian Talmud (17b) urges Jews not to reside in a village where there is no physician.

The attitudes of most Orthodox Jewish interviewees we found toward medicine and illness were very similar to contemporary *halachic* dealing with it. Taking into account God's omnipotence and humankind's freedom, both stress the necessity to save human life and to seek after medical treatment in case of illness, but at the same time not to overlook

God's role in illness and healing (Sinclair 2003, pp. 143-159) and to seek God's help in prayer (Tendler 1999, pp. 106-114). "It is always implied, however, that although the person may administer treatment, God does the healing: 'I am the Lord Who heals you' (Exodus 15:26)" (Isaacs 1998, p. 29). When a 'medical miracle' occurs, God remains the ultimate creator: "the physician is its conduit, not its creator" (Novak 2007, p. 95). As such, "medical practice articulates a covenantal relationship between God and the physician" (Sherwin 1990, p. 70). Thus, despite the *halachic* imperative to practice medicine when life is at odds, human beings may not become reckless and haughty. Orthodox participants in our study emphasized that physicians' freedom is circumscribed, because they are not equal to God. The physician, who is God's instrument, has to do as much as possible – walking within the lines of God's laws – but ultimately God is the true healer (Bleich 1981, pp. 1-10) and only God decides on life and death (Rosner 1999, pp. 99-105), a profound conviction which was found among the overwhelming majority of the Orthodox Jewish women who participated in our study. Although honoring the physician, the – for Jews apocryphal – book *Ben Sirach* states that medicine, doctors and health ultimately come from God.

While the views of the overwhelming majority of the Orthodox Jewish sample, having faith in an almighty God, were very similar to traditional Jewish convictions with regard to the role of God and human beings in creation, medicine, illness and death, these were (fundamentally) rejected by most secularized Orthodox Jewish participants, who were irreligious, and questioned by two Orthodox and two religious secularized Orthodox Jewish respondents, who had faith in a limited God.

6.4.2 Illness and suffering: divine exhortation toward repentance?

As is clear from our empirical findings, for religious Jews the pursuit of health is a central concern. Suffering is not considered as a value *per se* (Glick, 2006, pp. 119-129). Indeed, the Jewish religious tradition does not command to endure suffering nor to strive for it (Jotkowitz & Zivotofsky 2010; Steinberg 1999). Primarily, Jews are urged to live a healthy life – in his code of Jewish law, *Mishneh Torah*, Maimonides stresses the importance of preventive medicine and hygiene (Freeman & Abrams 1999, pp. 260-262; Weingarten 2007) – and, in this manner, to preserve the body God has given (temporarily) on loan to them and by which they stand in God's service (Sherwin 1990, pp. 78-81).

Despite this exhortation to fight illness, Jews who have faith in an almighty and merciful God, seem to object the view that illness and suffering are meaningless. As is clear from our empirical findings, the majority of the Orthodox Jewish sample tried to make sense of illness. A range of explanations were put forward. The Orthodox Jewish physician

Steinberg (1999) states that in Jewish history many explanations for suffering have been offered. Bowker's (1970) historical overview of Jewish theological attitudes toward suffering endorses Steinberg's statement. Already during the Biblical period two interpretations of suffering were offered: suffering as punishment for sin and as test of faith. These attitudes continued to live on in rabbinical thinking, although it was more and more stressed that disease and suffering come from God as a blessing and expression of mercy. Suffering, which is an inevitable aspect of human life, is considered to offer purification and a path toward repentance and atonement (Bowker 1970).

Our empirical findings show diverse tendencies with regard to coping with illness and suffering. The (overwhelming majority of the) Orthodox Jewish respondents in our study tried to make sense of illness and suffering, putting forward arguments which were strikingly similar to those of Orthodox Rabbi Bulka (1998). All the same, they acknowledged Steinberg's (1999) view, that God's reasons for human suffering are beyond human comprehension because human beings' knowledge is limited, in contrast to God's omniscience. God moves in a mysterious way.

According to Orthodox Rabbi Bulka, suffering is related to human failing and, in this way, to (the omnipotent) God. In his opinion God causes human beings to suffer as an expression of His concern for them and for their well-being. After all, experiencing suffering offers the ill person the opportunity to repent and to redeem his/her mistakes. For Bulka this view is completely consistent with a tradition that is concerned about the well-being of humankind. Suffering and repentance in this world guarantee purification from sin and, in this manner, everlasting life in the next world (*olam ha-ba*). In other words: the temporary earthly life – as ultimate test of faith – serves a higher, super-terrestrial purpose: eternal life in the hereafter. Similarly, Orthodox Jewish participants in our study acknowledged that illness is "for our own good". Thus, suffering is not necessarily a divine punishment. Rather, imposing illness and suffering is an affectionate divine act, a view that was found as well in the Orthodox Jewish sample of our study. Prospering in this world is only temporary, whereas suffering "is related to God's desire to purge them [the righteous] of any efficiency so that their ultimate reward of unencumbered reality is not denied them" (Bulka 1998, p. 39). Moreover, Bulka states that we have to keep in mind that nobody is perfect (Bulka 1998, pp. 83, 124). More than our interviewees did, he links human suffering to human failing, which is inevitable and fundamentally part of human reality, as *Ecclesiastes* 7:20 expresses: "Surely, there is not a righteous man on earth, who does good and doesn't sin". For Bulka, good and evil are free choices that result from our human existence: "We are all imperfect and this imperfection is a direct result of our being human. This does not diminish our righteousness" (Bulka 1998, p. 83).

For our Orthodox interviewees and for Bulka suffering stimulates seeking physical and spiritual healing. This does not only imply the Jewish mandate to consult a physician, but entails a spiritual exhortation as well: "soul-searching" (Bulka 1998, pp. 98, 105) and introspection. The ill person does not only have to aspire to physical healing, but he/she has to draw attention to the spiritual level as well, which means searching for the possible, more profound cause of one's suffering. Paying attention to this spiritual side of the picture makes one cultivate a positive attitude toward illness and suffering. Although this suffering is not worth striving after, it has – as "divine visitation" (Bulka 1998, p. 183) and "affliction of love" (Bulka 1998, p. 141) – a potentially constructive purpose. After all, the Jewish affirmative attitude toward life and death urges Jews to live through all moments of life meaningful. Moreover, the fact that the Jewish tradition is forward-looking – casting a look at the future world to come – effects that suffering can be endured meaningful. Although suffering is connected to our physical and psychological contingency and mortality – we can fail and sin – the Jewish tradition emphasizes, according to Bulka, that suffering – which might effectuate personal growth – indicates that man is very dear to God, an attitude distinctly found among Orthodox Jewish women who participated in our study. At the same time our Orthodox participants clearly expressed the view that the meaning of illness and suffering is beyond human comprehension, because human beings' knowledge is limited, in contrast to God's omniscience. Therefore "the necessity of the affliction" (Bulka 1998, p. 206) may not be questioned.

Similar to Bulka's views, the majority of the Orthodox Jewish sample in our study was of the opinion that disease is to do man good. It is part of God's meaningful plan with the world and with humanity. Given that God is good, God does not have the intention to tease or torment man. On the contrary, disease is considered to be a divine exhortation toward deeper faith and repentance, which (in the end) draws human beings closer to God. Accepting and enduring illness – which does not imply inaction with regard to medical treatment – serves a higher purpose: a purified entrance into the hereafter. In this sense illness is considered to be a divine blessing.

The secularized Orthodox sample held a dissenting opinion, either fundamentally rejecting faith in God, either rejecting God's contribution to human suffering, seeing an all-powerful God in contradiction with a benevolent God. This latter view – which we found among two non-Hasidic Orthodox participants in our study as well – is similar to Conservative Rabbi Kushner's outlook. He fundamentally disagrees with Bulka's analysis. Being confronted with the illness and death of his son, in his bestseller *When Bad Things Happen to Good People* Kushner (1981) questions – in the same way as some (secularized and non-Hasidic Orthodox) participants in our study did – Jewish faith in a merciful *and* almighty God: having faith in a God who is all-powerful (in the realm of misery) is in clear

contradiction with having faith in his goodness. In other words, for Kushner God's almightiness and righteousness are irreconcilable. From his personal reading of the biblical book *Job*, Kushner deduces God's mercifulness *and* restrictedness. Very similar to some secularized and non-Hasidic Orthodox participants in our study, he does not consider God as a God of power, who causes everything that happens to people, but as a God of righteousness, who suffers together with human beings and who supports them when they face misery. Given that God is limited, he cannot control everything what happens in the world. Therefore, in Kushner's view, God is not the cause of suffering; arbitrariness, the laws of nature and human choices are.

A literature review of Coleman-Brueckheimer and Dein (2011) revealed that Hasidim invoke religious explanations of illness. This finding is endorsed by our qualitative empirical study. Moreover, we found that in *all* researched groups (Hasidic Orthodox, non-Hasidic Orthodox, secularized Orthodox) religious convictions – image of God and of humankind, and the role of both in creation – seem to influence views on illness. From their qualitative research conducted among Haredi (strictly Orthodox) Jewish breast cancer patients in Londen, Coleman, Koffman, and Daniels (2007) draw a similar conclusion. The way the participants interpreted their disease was strongly influenced by their religious beliefs. Having faith in an almighty and good God – as in the majority of our Orthodox sample – one is more likely to understand illness as part of the almighty God's meaningful plan with humanity, which has to be accepted, as in the end it is for the good of human beings. In contrast to the study of Coleman, Koffman and Daniels we did not explicitly search for Jewish women with cancer to participate, nevertheless similar illness beliefs – illness as "part of a pre-determined and meaningful plan" (Coleman, Koffman & Daniels 2007, p. 127) and the interpretation of disease as a test – came to the fore.

On the other hand, someone who cannot accept the fact that God wants human beings to suffer and who considers God as a good, but restricted God, is more likely to state that human beings shoulder responsibility for evil in the world. This attitude was found among two Orthodox and two secularized Orthodox Jewish women. Obviously, having no faith in a transcendental reality – as was the case for the majority of the secularized Orthodox sample – one is more likely to consider illness as a purely profane fact, caused by human beings or misadventure.

6.5 Conclusion

Our explorative empirical study in the Orthodox Jewish community of Antwerp, Belgium endorses the Jewish folk saying "two Jews, three opinions". Judaism essentially is a religious tradition of diversity, which is reflected on a structural and organizational level in

its various branches grown throughout history. Moreover, an inner-denominational diversity among individual adherents of the Jewish religion and among its religious leaders is found. In the same way, Jewish views on illness cannot be brought under the same heading. Despite the discovery of dominant tendencies in the way in which Orthodox Jewish women deal with illness and suffering, dissenting views must not be overlooked.

Furthermore, this study shows that the way in which is dealt with illness and medicine is in an important way influenced by the religious convictions one holds on to. Rejecting faith in God, having faith in an all-powerful God or a benevolent God who is limited is reflected in the way one deals with illness and suffering in life.

The findings of this study might contribute to better practices in health care for Jewish people, on the basis of a greater understanding of specific Jewish illness perceptions and Judaism's inner diversity. A limitation of this study is the small number of participants, although consistent with the method of data analysis, given that theoretical saturation was reached. Being aware of the explorative and non-situational intent of the study – the sample did not purposively include ill women – it can provide a tentative basis for further (large-scale) research, in which the topics and findings can be explored in greater depth. One could wonder whether similar findings would occur from situational research. From the exploratory study of Coleman, Koffman and Daniels (2007) among strictly Orthodox Jewish breast cancer patients we are inclined to confirm this, yet taking into account the limited number (n=5) and very specific character (Haredi Jews) of their sample, further research appears useful.

7 "We are (not) the master of our body". Elderly Jewish Women's Attitudes towards Euthanasia and Assisted Suicide

7.1 Introduction

In Belgium, euthanasia and assisted suicide are widely debated (Broeckaert 2001; Verpoort, Gastmans & Dierckx De Casterlé 2004; Schotsmans & Meulenbergs 2005; Dierckx de Casterlé *et al.* 2006; Gielen, Van den Branden & Broeckaert 2008; Gielen *et al.* 2009; Broeckaert *et al.* 2009a), especially since the approval of a voluntary euthanasia act in 2002 (Belgisch Staatsblad 2002). While dominant ideological traditions – Christianity and non-religious humanism – have the floor in this debate on euthanasia, hardly any attention is paid to the practices and attitudes of ethnic and religious minorities, for instance, Jews. Nonetheless, it is obvious that Jews are also confronted with biomedical ethical challenges, and it is probable that the way in which they handle these challenges is heavily influenced by their own premises.

Studies conducted among health care providers (Davis *et al.* 1993; Young *et al.* 1993; Portenoy *et al.* 1997; Musgrave & Soudry 2000) and nursing students (Margalith, Musgrave & Goldschmidt 2003) found a more supportive attitude of Jews – in comparison with Christians – towards physician-assisted dying and voluntary euthanasia. This was endorsed by DeKeyser Ganz and Musgrave's (2006) findings in a study among Israeli nurses. Yet, in their study, they stressed the predominantly secular Jewish character of their sample. From their quantitative study among (mainly Jewish) Israeli oncology and non-oncology nurses, Musgrave, Margalith and Goldsmidt (2001) found that the more religious the nurses considered themselves, the less likely they were to support physician-assisted suicide. The study of Margalith, Musgrave and Goldschmidt (2003) among (mainly Jewish) nursing students confirmed that the degree of religiosity "was a significant determinant of attitudes towards PAD [physician-assisted dying]. The more religious students were, the less likely they were to support PAD". Indeed, religion or world view seems to influence the way one handles ethical questions (Gielen, Van den Branden & Broeckaert 2009a).

Aiming to bring forward different individual Jewish perspectives on the decisions of treatment at the end of life and being aware of a lacuna in relevant empirical research in this regard, a qualitative empirical research was performed in the Orthodox Jewish community of Antwerp. This article highlights the attitudes of elderly Jewish women, belonging to this community, with regard to euthanasia and assisted suicide and explores how these attitudes reflect their fundamental religious convictions and practices.

Jews have been living in Belgium for centuries. Their presence stretches back to the thirteenth century (Brachfeld 2000; Abicht 2006), and historically, the Jewish population has increased as a result of different migration waves, especially in the sixteenth, nineteenth and twentieth centuries (Schmidt 1994; Saerens 2000; Abicht 2006; Vanden Daelen 2008). On the eve of the Second World War, an estimated 65.000-75.000 Jews lived in Belgium (Saerens 2000; Vanden Daelen 2008). After liberation in 1944, this number was decreased to barely 20.000 (Vanden Daelen 2008). Today, approximately 40.000-50.000 Jews live in Belgium (Abicht 2006; Vanden Daelen 2008). The two largest communities are found in Brussels and Antwerp.

In contrast to the community in Brussels, which also houses a liberal Jewish community, Antwerp Jewry is essentially Orthodox (Abicht 2006). The estimated 15.000-20.000 Jews in Antwerp belong to one of the following Orthodox communities: Machsike Hadas, Shomre Hadas or the – rather small – Portuguese community. Moreover, a significant group of Hasidic Jews – associated with diverse Hasidic sects (Robberechts 1990, pp. 270-275; Gutwirth 2004) – live in Antwerp. However, the essential Orthodox character, which is ascribed to the community, does not result in a stifling of diversity. To date, no current data exist concerning an exact number of the Jewish population in Antwerp (and Belgium); only estimated data can be indicated. About 25% of Antwerp Jewry is Hasidic (Gutwirth 2004), about 40% is non-Hasidic Orthodox and about 35% secularized Orthodox. Whereas for Orthodox (Hasidic and non-Hasidic) Jews being Jewish means following the stipulations of Jewish law, secularized Orthodox Jews interpret their Jewish identity in ethnic and cultural terms. For them, being Jewish essentially means that they belong to the Jewish community and strive for its continuation by passing on the Jewish tradition and culture. They characterise themselves as "traditionalist" or "non-practising" Jews, referring to a reduced Jewish praxis which is maintained out of habit or tradition: the celebration of some important Jewish holidays and the practice of Jewish rituals that mark important moments in life (such as circumcision, religious marriage, burial). As such, they can also be characterised as 'secularized Orthodox' Jews. This may sound paradoxical. Indeed, the paradox consists in the fact that they distance themselves (partially) from the Orthodox Jewish tradition – they do not (want to) consider themselves Orthodox since they do not follow (all) the stipulations of Jewish law. Yet, at the same time they insist on being seen as members of the Orthodox Jewish community (of Antwerp), which provides them with facilities for Jewish rites of passage, which act for them as important Jewish identity markers.

7.2 METHODS

From June 2008 until January 2009, 23 semistructured interviews were conducted with a purposive sample of elderly (age 60-75 years) Hasidic, non-Hasidic Orthodox and secularized Orthodox Jewish women in Antwerp (Belgium). The face-to-face interviews were conducted in Dutch in the interviewees' home, following grounded theory methodology (Glaser and Strauss 1967, Strauss and Corbin 1998), making use of a semistructured topic list on religion, ageing, illness, death and treatment decisions in advanced disease. The interviewees were also asked to provide some demographic information about themselves. In order to gain insight into the participants' religious and ideological convictions and practices, a set of questions was developed for which we relied on the multidimensional religiosity measurement model of sociologists Glock and Stark (1966). They draw a distinction between five "core dimensions of religiosity" (Glock & Stark 1966, pp. 19-20) – ideological, intellectual, ritualistic, experiential and consequential – and we added a social dimension of religiosity. For these categories we phrased a number of questions.

Attitudes towards treatment decisions at the end of life were explored making use of hypothetical cases that were formulated on the basis of the typology of Broeckaert (2006; 2008; 2009a; 2009b). With the respondents' consent, the interviews were recorded. On average, each interview took 99 minutes. Data collection continued until theoretical saturation was reached, i.e., when no new elements and insights came forward from further interviewing. After the interviews had been conducted, they were transcribed verbatim and anonymised making use of pseudonyms. The grounded theory methodology was used to code and analyse the interview data. By adding codes to the data and through constant comparisons, key concepts were identified in the interviews and categories were systematically generated and interrelated. For the data analysis, a qualitative software package was used. As this article focuses on the attitudes of elderly Jewish women towards euthanasia and assisted suicide, only these findings – and the interplay with religion – will be presented.

In the typology developed by Broeckaert (2006; 2008; 2009a; 2009b), choices with regard to euthanasia and assisted suicide constitute one category of treatment decisions at the end of life (apart from choices with regard to curative/life-sustaining treatment and pain/symptom control). Although it is clear that the central characteristic of this category is the intention to end or shorten a patient's life, further differentiation is appropriate. Broeckaert distinguishes three kinds of acts belonging to this category: (1) non-voluntary euthanasia, which is "the intentional administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable, not at this patient's request"; (2) voluntary euthanasia, which is "the intentional

administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable by the patient, at this patient's request"; (3) assisted suicide, which means "intentionally assisting a person, at this person's request, to terminate his or her life" (Broeckaert 2009a, p. 111). The hypothetical cases developed on the basis of this typology are mentioned below.

Case 1: voluntary euthanasia

A terminal patient, having only a few more weeks to live, is in severe physical pain. The treating physician has been unable to adequately relieve his or her pain. That patient requests his or her life to be ended. Should the physician administer a lethal injection?

Case 2: assisted suicide

A terminal patient, having only a few more weeks to live, is in severe physical pain. The treating physician has been unable to adequately relieve his or her pain. The patient requests medication to end his or her life. Should the physician provide drugs so that the patient can end his or her life?

Case 3: non-voluntary euthanasia

For several months a patient has been in an irreversible coma, breathing spontaneously (artificial nutrition and hydration are administered). Should the physician be allowed to administer a lethal injection to end the life of the patient?

7.3 RESULTS

7.3.1 Participants' background and religious identity

The 23 participants were aged between 60 and 75 years, with a mean of 65 years. Twelve respondents lived in Belgium before the Second World War. Eleven respondents migrated to Belgium after the war. Thirteen participants were born in Belgium, two in the Netherlands, three in Switzerland, one in Indonesia, one in Uzbekistan, one in France and two in Israel. The mother language of six of the participants was Yiddish, five participants had Dutch as their mother language, four interviewees French, two respondents English,

two participants German and one interviewee Hebrew. Three interviewees had two mother languages: two Dutch-French and one Polish-Yiddish. The overwhelming majority of the women were multilingual, mastering a total of between three and nine languages. Seventeen interviewees were married, three were divorced and three were widows.

Orthodox women had noticeably larger families (with up to 10 children) than did secularized Orthodox Jewish women (up to four children). All Orthodox participants lived in the neighbourhood of Antwerp's Central Railway Station and the diamond quarter – where most facilities needed to lead an Orthodox Jewish life are found (Gutwirth 1970) – contrary to the majority of the secularized Orthodox respondents. Eight interviewees were secularized Orthodox, nine were non-Hasidic Orthodox and six were Hasidic. While the majority of the secularized Orthodox Jewish respondents considered themselves as not religious or as indecisively religious, every Orthodox participant reported that she was (very) religious.

7.3.2 Participants' attitudes towards euthanasia and assisted suicide

7.3.2.1 Voluntary euthanasia

While almost all of the secularized Orthodox Jewish respondents were in favour of voluntary euthanasia, all Hasidic interviewees were found to be absolute opponents. The other Orthodox respondents held a rather intermediate position. For the secularized Orthodox participants, the patient's self-determination with regard to his or her quality of life was of overriding importance.

> And if that, on that moment, is really your decision, why not? Why can you make decisions during your whole life, for sixty, seventy years, 24/24, and then you should not take the most important decision in life? [...] You only have one life, and I think, you can have a say in it, in your own life. (Ruth)

Josephine was the only secularized Orthodox respondent who felt uncomfortable with confronting the issue of euthanasia. According to her, performing euthanasia stands in sharp contrast with a physician's Hippocratic oath. As such, a physician's task is to save life, not to shorten it. All the same, for her a patient's wish should be respected. The interviewees who agreed with the act of euthanasia referred to the patient's unbearable suffering as inhumane. They were of the opinion that the patient's life did not posses any sense of quality and his or her life was no longer meaningful. Nevertheless, for them the request for euthanasia had to be conscious and deliberate.

> I think that, if someone suffers and no amelioration is possible and no normal life is possible, then this life does not have to consist merely of unbearable pain. Because for me this is no longer quality of life. (…) (Ruth)

> There's no hope. I mean, what's the meaning of his life? Is it still meaningful? I mean, does it offer him something positive? I don't think so. (Dianne)

> Yes he can, but according to the Jewish religion he can't. But with regard to this I'm more modern. I say yes. […] Because the patient does not have to suffer. He must not suffer. What's meaningful about suffering, crying, suffering? It's not necessary. (Lisa)

For all of the non-Hasidic Orthodox respondents, euthanasia was found to be irreconcilable with being an Orthodox Jew, as this treatment decision is forbidden by Jewish law. Sarah gave a very short, negative answer towards the issue. Danielle was rather uncertain about it and referred the interviewer to a rabbi. Moreover, she pointed out that a physician has limited knowledge while God is omniscient. The other non-Hasidic Orthodox interviewees acknowledged a human being's free will. Thus, although euthanasia is forbidden according to Jewish law, it is still important that everyone decides for oneself. Yet, Elizabeth and Tzippa distinguished between a non-Jewish patient – who can ask for euthanasia – and a Jewish patient – who should not. Elizabeth stated: "If I were not Jewish, I would be in favour of euthanasia". The participants emphasised that although Jews are free to make choices, in the end their actions will be judged by God.

> Yes, a patient can certainly ask that, but from my Orthodox point of view I am not allowed to ask that and my people will not ask this as well. Do you understand? (Tzippa)

> The Jewish religion strongly emphasizes human beings' own responsibility. […] You are in front of God and you do what you want in that case. But it is certainly forbidden. (Elizabeth)

Although these two examples showed an acknowledgement that Jewish law prohibits active termination of life, some participants expressed their understanding for people who might choose voluntary euthanasia. Tamar and Norah seemed to deplore the fact that Judaism prohibits euthanasia because it is understood that for some patients it could offer a way out of unbearable suffering. Yet, they mentioned their desire to live a consistent Orthodox Jewish life: they want to stick to all the Jewish commandments, inciuding the obligation to respect and preserve human life.

> Very difficult question. It is not allowed but it's not correct. (Tamar)

> Actually, I have talked it over with my husband. I think it's okay. But it's not practised in our religion. [...] I don't think we are made to suffer on earth. [...] Religion has a lot of positive sides. And you have to accept – nothing is perfect (laughs) – the rest. (Norah)

The only non-Hasidic Orthodox Jewish respondent who openly distanced herself from Jewish law, declaring herself a convinced supporter of euthanasia, was Esther. For her, the unbearable suffering of the patient in the hypothetical case was the decisive factor.

> - According to me, yes. But it is not allowed according to the, euh, religion.
> - But for you it is?
> - For me, yes.
> - So according to you, a patient can ask a physician 'please give me an injection' or ...
> - Yes, if he suffers unbearable pain. And he does not want to live any more. For me, yes. I do know that it's against the religion. (Esther)

Given the other Orthodox interviewees' disapproval of euthanasia, Esther's appreciation of active termination of life in the presented hypothetical case was rather surprising. In the 'Discussion' section, it will be explained that her deviant answer correlates to her personal religious convictions and image of God. Moreover, her reaction may have to do with her own medical history – she is a breast cancer survivor.

Unlike the non-Hasidic Orthodox women, the Hasidic women left no room for euthanasia. All of the interviewed Hasidic women declared themselves as absolute opponents of euthanasia, because Jewish law forbids it. Jewish law focuses on the idea that human beings do not own their bodies, and thus, they cannot pass judgement on God's property. Moreover, after death, God will judge human beings by their actions. Hasidic respondents do not make a distinction between their personal opinion and the viewpoint of Jewish law.

> You know what I will answer. That's, that's not easy. Life is not so easy. But, when we come with a purpose. And we know that we are not the boss and the body is not mine. I have a, I will face the consequences up there. You understand? Then I think differently. (Devorah)

Chaya and Nechama argued for a better pain relief programme as an alternative solution. Although she did not approve of euthanasia, for Suzannah, asking for euthanasia

was quite understandable. According to her, we cannot pass judgement on another human being's actions.

> I can understand when one suffers unbearable pains and if one cannot, if one cannot do anything about it, one cannot alleviate it or whatever, then I understand that that person asks this. But, euh, the answer, euh, that is not my answer. (Suzannah)

From the participants' reactions to the case it is clear that while in the secularized Orthodox interviewees' answers no reference was made to the Jewish religion or God, this reference was prominently present among the other participants. While for them God's sovereignty in the domain of life and death and the primary Jewish imperative to save life were decisive arguments for disapproving of euthanasia, the secularized Orthodox respondents – being not religious or having faith in a good and limited God who is powerless to do anything about human beings' suffering – dealt with this ethical dilemma on a purely profane level. The patient's unbearable suffering was the most decisive argument for the proponents of euthanasia in this group. This was also the case for Esther, the only (non-Hasidic) Orthodox participant who explicitly approved of voluntary euthanasia. In the 'Discussion' section, we will expand on the interplay between her opinion and her religious convictions.

7.3.2.2 Assisted suicide

The respondents' opinions on this case were similar to their attitudes towards voluntary euthanasia. Again, significant differences between the three groups of participants were detected. While the secularized Orthodox Jewish respondents were in favour of assisted suicide, the Hasidic interviewees were diametrically opposed to it. Again, the non-Hasidic Orthodox participants held an intermediate position. All secularized Orthodox respondents emphasised the patient's suffering and his or her free choice; however, they said that when one is choosing for assisted suicide it has to be done in careful consultation with close family members and physicians.

> Yes. But again the same circumstances as the other. So, if you do this surrounded by your family and friends and by physicians and nurses and whatever. And if you do this consciously, as you cannot stand this anymore, and you absolutely do not want to lead this kind of life. Why not? Why not? After all, we are mature beings isn't it? We are taught to, to, to live independently as much as possible, to, to, grow up, to, to… then you have to be consequent. Then you cannot suddenly draw a line and say 'So, now

> you are ill, so from now on you become 100% dependent from another human being and we will tell you what you have to bear or not'. That seems not logical to me. (Ruth)

There were only two non-Hasidic Orthodox reactions on the case that were extremely negative. Sarah and Danielle openly dissociated themselves from assisted suicide, expressing the belief that a human being cannot – but only God can – set his or her date of death. As an alternative solution, Danielle suggested better pain relief.

> No, it is shortening of life. He is no more in position to judge what is good for him. (Sarah)

> Then they have to find another remedy. That's the only solution. They have to find another remedy to relieve pain. (Danielle)

Among the non-Hasidic Orthodox women, only Elizabeth's and Esther's answers on the case were affirmative. Elizabeth's reaction was rather surprising, as she mentioned in the previous case that Jewish law disapproves of a deliberate termination of life. With regard to this decision, she stated that she was not familiar with the viewpoints of Jewish law on the matter.

> - Do you ask that according to Jewish law or according to me?
> - According to you, your opinion.
> - Ah, according to me, but why do you have to ask Orthodox Jewish women? You can ask it to everyone. Everyone is the same in this. Whether the doctor is allowed to do this? I think that it, that for the patient it is nice. I would consider it nice to have such a thing, that possibility. [...] According to Jewish law, I don't know. Ask a rabbi. I don't know how it is according to Jewish law. I don't know. [...] According to me, yes, I would like that. I would like that, yes. (Elizabeth)

Similar to her reaction on euthanasia, Esther again distanced herself from Jewish law: according to her, a patient always has the right to self-determination. Again, we noticed an obvious interplay between her viewpoint on this matter and her religious beliefs. We will further elaborate on this topic in the 'Discussion' section.

The other non-Hasidic Orthodox respondents emphasised that – even if one personally, in theory, agrees with assisted suicide – living as an Orthodox Jew is irreconcilable with a deliberate termination of life. For an Orthodox Jewish patient to request for assisted suicide would not be feasible in practice, as this is against Jewish law.

Yet, the patient's autonomy is recognised, and for Norah, requesting for assisted suicide in a situation where a terminal illness is present was completely understandable.

> - I actually think that, I say 'I follow the rules', so I say 'no' for the rules but personally I think that it is good.
> - Yes, that the patient can decide for himself ?
> - I think as a human being suffers, that's the worst in life. There is nothing worse than suffering. (Norah)

All Hasidic interviewees expressed their disapproval of the case. According to them (assisted) suicide is strictly forbidden for Jews. They stressed that Jewish law condemns deliberately terminating life as God is the only author of life and death. Better pain and comfort treatment was suggested as an alternative solution. Although Suzannah agreed with the other respondents, she warned them for passing judgement on other human being's actions.

> - NO! Suicide!
> - Well, it is called assisted suicide.
> - No (indignant). (...) Suicide. No. (...) That is suicide. (...) Out of the question. Not by means of an injection, not by means of drugs, by no means. You do not decide when you come into the world. You do not decide when you die. You do not ask to be born neither, isn't it? (Leyla)

Again, the participants' world view and religious convictions were implied in their reactions to the presented case. While among the secularized Orthodox participants no reference to a transcendental reality or God was made, there was a very strong emphasis on heteronomy, in contrast to human autonomy, among the other participants. Indeed, the Orthodox Jewish participants' belief that only God has the right to determine the time of death, as He is almighty (in contrast to human beings' restrictedness), was again a crucial argument for denouncing active termination of life. Only Esther proved to take a deviant stance on this.

7.3.2.3 Non-voluntary euthanasia

To the Hasidic respondents, non-voluntary euthanasia was absolutely forbidden, while we noticed a small openness for this decision among a few non-Hasidic Orthodox and secularized Orthodox Jewish respondents. Yet, only two secularized Orthodox Jewish participants absolutely approved of non-voluntary euthanasia in the hypothetical case,

since, according to them, being in an irreversible months-long coma impugns a person's dignity.

> It's not dignified. It's not dignified. I want, I want dignity at the end of life, that's, that's what interests me, dignity. Value, dignity. Nothing else. (Leah)

In contrast to this view, two secularized Orthodox interviewees were unfavourably disposed towards the case for a few reasons: as Joanna was wondering whether the coma was in fact irreversible, she suggested to wait and see, and Josephine warned against malpractice and she referred to a physician's Hippocratic oath and his or her duty to protect human life.

> Oh (...) (sighs) Unfortunately, we do not know whether it is irreversible. This means that nobody can decide on this. And if a patient gives no sign of discomfort or pain (...), no one can decide on this. Then it has to, yes, continue as good as infinitely, until he dies spontaneously. (Joanna)

The other secularized Orthodox Jewish respondents were indecisive with regard to the case. They did not consider active termination of life without the request of the patient *a priori* unacceptable. For them, this decision depends on the context and circumstances and on the patient's philosophy. If all (close) family members would agree that the patient would have opted for active termination of his or her life, this (unwritten) will has to be followed. Nevertheless, this decision cannot be taken rashly.

> But euh, I think that in this case it's hard to make a decision. That euh, because the body functions. (...) Because there is still, when there is still hope, OK. Then I would not, yes, I would not want to be the authority who says 'that person has the right to wake up' or 'it is enough for us, we spent enough money' (...). Yes, except for when, I say, except for when the whole family agrees that he was this kind of person who absolutely did not want this, who did not want to wake up crippled or, he, so who did not want that in any case. These are difficult cases, I think it has to be considered case by case. These are not matters from which you can draw a general conclusion. I really think this has to be considered, thought over case by case, and certainly no quick decisions must be made. These decisions must be thought over for one or two years. (Ruth)

According to the majority of the non-Hasidic Orthodox interviewees, active termination of life without the request of the patient was absolutely forbidden. All of the respondents, including those who were rather indecisive on the case, considered it as

contrary to Jewish law and irreconcilable with leading an Orthodox Jewish life. A few respondents even used the word "murder".

> - No, that does not exist among us, no. If, in orthodoxy you can not do that, give an injection.
> - OK. Can you explain why this …?
> - No, we, we are not going to decide on a person's death. That is, that is not, euh, we don't do that. (Tzippa)

For these interviewees, only God decides upon the termination of life and human beings do not have the right to pass judgement on life. The only appropriate attitude to take is to accept the situation and wait and see. Although all respondents referred to the fact that this decision would completely contradict Jewish regulations, a few among them had reservations. Identifying themselves with the patient in the case, Tamar, Norah and Esther made a distinction between what they would want for themselves (active termination of life) and what Jewish law prescribes (non-voluntary euthanasia is forbidden). At the same time they were also aware of the risk of abuse and family members' guilty conscience in case they would decide to end the patient's life.

> If I would be in that situation, I would say 'yes, do it', but I cannot decide for others. If I was in that situation, I would want it for myself. […] The patient himself, if he could ask for it, maybe he would choose for it. But the family, I don't think so. I don't think so. I would have a guilty conscience forever. […] The decision to end life may not come from human beings. Then there will be so much abuse. If it is one hundred percent . . .but there are people waiting for their inheritance. (Tamar)

> On the one hand, I would say yes. But I think that the person who would decide this would live with a guilty conscience. Because, you kill someone. That person is alive. He is not attached to machines, so he breathes and. So, euh, it is no life, it is not pleasant, but it is like that and you have to accept it. (Esther)

Among the Hasidic women, Chaya also alerted us, referring to the Holocaust, to the dangers of abuse. Yet, the most decisive reason for disapproval of the case was the religious conviction that only God is the author of life and death. All respondents declared that the decision to end human life is not up to human beings. The situation must be accepted, and thus, the individuals involved in the case should wait and see what happens. In this way, all of the Hasidic respondents were unanimously against non-voluntary euthanasia.

NO! That is killing! (Chaya)

- NO! Certainly not. Cent pour cent. That is euthanasia! No, forbidden, forbidden! Certainly not.
- Why not?
- Because we do not decide on life and death. I told you, only God decides when he dies.
- So, he. So, that patient can actually be in a coma for months, years…?
- Years also, he, yes, yes.
- And nothing can be decided?
- No. God decides. Yes. Even if he lives like a plant. (Leyla)

The interviewees believed that human beings are not the owners of their bodies. Thus, deciding on human life would be playing God and deciding on God's property. For the Hasidic respondents, there was still hope in this situation because of the belief that God moves in mysterious ways.

What do you think? […] That is not allowed. You understand? That is not allowed. We are not the master of our body. That is not, we are not here for ourselves alone. That is, you ask, I am a little part of God; And I have no power over my body and I am not allowed. […] I act according to the doctrine, very simple. (Devorah)

No […] Because he shortens life. He's playing God. (Suzannah)

The arguments for rejecting non-voluntary euthanasia among the secularized Orthodox interviewees on the one hand and the (non-)Hasidic Orthodox participants on the other hand were essentially different. While among the Orthodox participants God's sovereignty was used as a decisive argument for denouncing non-voluntary euthanasia, God did not come to the fore in the secularized Orthodox women's argumentation. For them, the autonomy of the patient was the key value. Some mentioned the slippery slope argument, as they warned for risks and dangers of abuse, yet without referring (in contrast to the (non-)Hasidic Orthodox participants) to God as the absolute sovereign in the domain of life and death.

7.4 Discussion

The debate on euthanasia in Western Europe is often approached from the point of view of the dominant Western ideological traditions, Christianity and non-religious

humanism. From this perspective, a lot of literature has been written on the interplay between religious/ideological convictions and ethical attitudes with regard to euthanasia and assisted suicide. A considerable number of studies among health care professionals worldwide have shown an influence of (the intensity of) religious belief on the willingness to endorse euthanasia and assisted suicide (Ward & Tate 1994; Sorbye, Sorbye & Sorbye 1995; Bachman *et al.* 1996; Di Mola *et al.* 1996; Portenoy *et al.* 1997; Grassi, Magnani & Ercolani 1999; Willems *et al.* 2000; Emanuel 2002; Ryynänen *et al.* 2002; Sprung *et al.* 2003; Cuttini *et al.* 2004; Müller-Busch *et al.* 2004; Miccinesi *et al.* 2005; Rurup *et al.* 2005; 2006; Sprung *et al.* 2007a; 2007b; Cohen *et al.* 2008;Gielen, Van den Branden & Broeckaert 2008; Broeckaert *et al.* 2009a; 2009b; Gielen, Van den Branden & Broeckaert 2009a; Inghelbrecht *et al.* 2009; Seale 2009). Likewise, studies among the general public have generally shown that endorsement of euthanasia and assisted suicide decreases as the intensity of religiosity increases (Genuis, Genuis & Chang 1994; Caddell & Newton 1995; Achille & Ogloff 1997; MacDonald 1998; DeCesare 2000; Emanuel 2002; Ryynänen *et al.* 2002; Burdette, Hill & Moulton 2005; Rietjens *et al.* 2005; Rurup *et al.* 2005; Cohen *et al.* 2006; Chong & Fok 2009). A great amount of bioethical literature on euthanasia, written from a Jewish perspective, has been published (Bleich & Rosner 1979; Bleich 1981; 1993; Rosner 1986a; 1986b; 1995; Sherwin 1990; 1995; 1998; 2000; Jacob & Zemer 1995; Zohar 1997; Dorff 1998; Falk 1998; Jacob 1998; Kaplan & Schwartz 1998; Mackler 2000; Gesundheit *et al.* 2006; Hurwitz, Picard & Steinberg 2006) in contrast to empirical research on the topic. Our explorative qualitative empirical research in the Orthodox Jewish community in Antwerp (Belgium) aims to meet this lacuna.

In our empirical results an interplay between ethical attitudes and religious convictions clearly comes forward, especially considering one's image of God and to what extent one agrees with the essentials of the Jewish religion's influence on one's attitude towards active termination of life. The majority of the secularized Orthodox Jewish participants called themselves non-religious or indecisively religious. Only two respondents considered themselves as religious. Yet, they did not believe that God is almighty. All secularized Orthodox respondents were of the opinion that God does not play a role in disease or death, given that for them God does not exist or God is a good and limited God who is not responsible for everything that happens in the world. For these interviewees, illness and death were merely profane facts. Thus, when discussing euthanasia and assisted suicide God did not come to the fore. Moreover, as their Jewishness has no religious connotation, the prescriptions of Jewish law were rarely, if ever, mentioned. Frequently referring to the importance of the autonomy and the quality of life of a human being, treatment decisions were discussed on a profane level, without taking note of a heteronomous, transcendental reality. Pushing for a personal right of self-determination with regard to life and death, the overwhelming majority of these secularized Orthodox

participants were in favour of voluntary euthanasia and assisted suicide. Given this strong emphasis on a patient's autonomy, it is understandable that non-voluntary euthanasia was disapproved by the majority of them: active termination of life without the request of the patient would be a denial of the patient's right of self-determination. Thus, active termination of life without the patient's request was not rejected because the participants imbibed certain values of the Jewish faith (such as the importance of preserving life). Indeed, the ethical attitudes of the secularized Orthodox participants did not reflect convictions or values of Orthodox Judaism. On the contrary, they explicitly turned away from Jewish Orthodoxy, often being very critical towards it, and this was obvious in their ethical reasoning. In this sense, their ethical position was more in keeping with a secular atheist way of thinking than with Orthodox Jewish ethical viewpoints.

All Orthodox (Hasidic and non-Hasidic) Jewish respondents considered themselves as religious Jews, who follow God's laws. They reported experiencing the presence of a Creator God, who created the world and humankind, in their lives. While Esther and Norah doubted God's omnipotence, for the overwhelming majority of the non-Hasidic Orthodox and for all Hasidic interviewees it was expressed that God was understood as almighty and omniscient, that everything – life, death, illness, healing, etc. – is believed to be in God's hands. Furthermore, it was expressed that only God knows why God causes disease and death, and since God is infinitely good, God's judgement is correct and for the better. God was also indicated as having a meaningful plan with the world, and the overwhelming majority of the Orthodox Jewish respondents reported that they completely trusted in God. This ultimate trust in God was expressed through the (strict) observance of Jewish law, which was understood by them as an articulation of God's will towards humanity. Observing God's will (Jewish law) hallows God's name and is for the good of human beings. It was expressed that cultivating a faithful relationship with God guarantees reward in this life or in the world to come. As this orthodoxy and, especially, orthopraxis – performing good deeds – were expressed as being very central to the Orthodox respondents, every decision, according to the respondents, thus has to be taken in accordance with Jewish law and must be an expression of serving God and putting trust in God's plan. Given that the Torah makes clear that God is the ultimate owner of the human life and body, for the overwhelming majority of participants, deliberately terminating human life – with or without the patient's request – was not open for discussion.

The argument that human beings cannot control life and death decisions was also put forward by elderly Jewish people in the qualitative empirical study of Leichtentritt and Rettig (1999). However, this study emphasised that their results did not entail a rejection of human beings' free will. In our study, the Orthodox interviewees, non-Hasidic women in particular, made reference to a patient's right towards self-determination (yet a Jew is

expected to choose according to Jewish law). A few non-Hasidic Orthodox respondents approved of active termination of life. Esther, for instance, was a convinced supporter of euthanasia. Even in this case, there was every indication that her attitude was influenced by her religious convictions. Esther refused to have faith in an almighty God who might be understood as one who decides on misfortune. She expressed her faith in a good and limited God. As such, to her, illness is merely a profane fact and is not caused by an all-powerful God, who ultimately sets the time of death. Therefore, for her making the decision to terminate one's own life was seen as not acting against God's will and did not disprove one's trust in God. For her, it was understood that one is not acting in a contradictory manner to choose one's own life to be ended and to have faith in God at the same time. Elizabeth's argument for approving assisted suicide was unclear. She indicated that she was not well-informed of the viewpoint of Jewish law on this matter.

Quantitative studies among (mainly but not exclusively) Jewish nurses (Musgrave, Margalith & Goldscmidt 2001; DeKeyser Ganz & Musgrave 2006) and nursing students (Margalith, Musgrave & Goldschmidt 2003) endorse our findings that (the degree of) religiosity plays a significant role in (dis)approving active termination of life. Wenger and Carmel (2004) surveyed Jewish physicians to describe the relationship between religiosity and end-of-life care. Likewise, from their quantitative empirical study they found that very religious physicians, compared to moderately religious and secular physicians, were much less likely to approve of euthanasia. In the qualitative empirical study of Leichtentritt and Rettig (1999), in which 36 elderly people in Israel were interviewed with regard to end-of-life preferences, adherence to religious beliefs was one of the arguments put forward to disapprove of euthanasia. Because of the qualitative nature of our empirical research and through in-depth interviewing we were able to pursue the question of the religion-ethics interplay in greater depth. From our data we are inclined to infer that one's image of God has a stronger effect on one's attitudes towards euthanasia than being (ir)religious. In our findings, respondents who outrightly rejected faith in a transcendental reality and interviewees who had faith in a limited God, who does not cause misfortune, were more likely to stress a patient's right to self-determination with regard to his or her life and death, while interviewees who put trust in an omniscient, almighty creator and governor of the world who decides on fortune and misfortune and who is the ultimate possessor of human life and body were more likely to disapprove of euthanasia and assisted suicide. Noting this complex interplay between religion and ethics, the image of a transcendental reality or of God as being a significant influential factor for (non)acceptance of euthanasia, it would be interesting to explore religious liberal – for instance, Reform Jewish – attitudes on the matter. As mentioned, this group was not included in our empirical research, because Antwerp does not house a religious liberal Jewish community.

In order to elicit the attitudes of ethnic and religious minorities, especially with regard to delicate topics, qualitative empirical research proves to be most adequate. More than studies with a quantitative empirical research design, qualitative empirical studies provide opportunity for in-depth interviewing and analysis. They allow for eliciting the complexity in ordinary people's way of thinking. For instance, although being a very religious Orthodox Jewish woman, Esther's response to euthanasia proved to be different from the answers of the other Orthodox Jewish participants. Through in-depth interviewing we discovered that this was due to her individual and particular image of God. As this study aims to fill the lacuna in empirical studies of Jewish perspectives on end-of-life decisions, for instance, euthanasia – in contrast to a significant amount of publications written on the topic from a theoretical Jewish perspective – this study has some important implications for contemporary clinical practice, which deals with 'the man on the street'. Indeed, ordinary religious people's viewpoints may differ from theoretical or doctrinal positions. In Jewish ethical decision-making, for instance, a case-based approach predominates (Jakobovits 1997): rabbis address ethical questions of individual Jews on a case-by-case basis. Considering their specific dilemmas and circumstances (bottom-up), rabbis address biblical and rabbinic sources in order to find proper precedents, which are in turn applied to the case at hand (top-down) (Newman 1992, p. 311). As such, theoretical Jewish discussions on a particular ethical dilemma may differ from real-life decisions (Kellner 1995). Thus, given the specific context of each case, decisions on similar ethical dilemmas may vary (Glick 1997).

Jewish understandings of ethical dilemmas in healthcare, such as euthanasia, might be different from dominant Western (Catholic or secular) outlooks on it. Meeting the healthcare needs of Jewish patients supposes acquaintance with their specific religious and ethical viewpoints. At the same time, healthcare professionals should be aware of the fact that religions and world views are not monolithic. Judaism, for instance, has several religious branches and being Jewish does not define one's religiosity. Similarly, diversity was found in our sample. Thus, when caring for Jewish patients it is indispensable to get acquainted with their personal religious convictions.

Yet, despite Judaism's essential diversity, there is a general trend in (religious) Judaism to emphasise the absolute value of human life (Jakobovits 1959; Rosner 1986a; 1986b; 1999; Tendler & Rosner 1993; Freedman 1999; Glick 1999). Indeed, in different religious branches of Judaism, a dominant cautious attitude towards quality of life judgements (Schostak 1991; Mackler 2003, p. 108; Zohar 2006, p. 2) is found and religious Jewish voices in favour of active termination of life are rather exceptional (Gesundheit *et al.* 2006; Baeke, Wils & Broeckaert 2011a). Moreover, although recognising the autonomy and responsibility of human beings, Judaism generally opposes an unbridled right to self-

determination. The Jewish religious tradition does not stress the rights human beings have, but their duties (towards God and fellow human beings) (Jakobovits 1989; Freedman 1999; Goldsand, Rosenberg & Gordon 2001; Jotkowitz 2009; Jotkowitz & Glick 2009b). Through adequate training and clear guidelines, nurses and physicians can be informed about the specifics of dealing with (religious) Jewish patients, such as the importance of taking the delicacy of ethical dilemmas involving (active) termination of life into account, and the potential involvement of rabbinic authorities in medical decision-making, especially among (strictly) Orthodox Jewish patients (Coleman-Brueckheimer, Spitzer & Koffman 2009). It is important to note that the Jewish ethical system "has evolved more as a form of casuistry rather than as a list of principles" (Glick 2003, p. 119).

Given the specific way people with diverse religious and cultural backgrounds deal with health, disease and ethical dilemmas in healthcare, contemporary Western societies must be concerned with offering culture-sensitive care (Gesundheit 2010; Jotkowitz, Glick & Zovotofsky 2010a; 2010b). Indeed, in contemporary Western healthcare the need felt to deal with cultural and religious plurality is high, which is, for instance, evident from different hospitals' steady requests to our centre[1] for training and clear guidelines in this regard. Evidently, policy-makers play a huge role in this, considering the fact that in debates on healthcare policies, differing views of diverse religious traditions which are strongly embedded in Western European countries, should be consulted. Policy-makers and healthcare professionals should be aware of the fact that patients must be approached holistically, paying attention to their specific context, religious views and ethical attitudes. Moreover, they must realise that giving attention to a patient's religious or ideological identity may not be restricted to offering spiritual guidance. Indeed, religion and world view might play an important influential role in dealing with illness and making concrete medical decisions (at the end of life) (Carmel & Mutran 1997; Leichtentritt & Rettig 1999; Ejaz 2000; Musgrave, Margalith & Goldsmidt 2001; Margalith, Musgrave & Goldschmidt 2003; Wenger & Carmel 2004; DeKeyser Ganz & Musgrave 2006; Coleman, Koffman & Daniels 2007; Coleman-Brueckheimer, Spitzer & Koffman 2009; Gielen, Van den Branden & Broeckaert 2009a).

In sum, offering care, which is sensitive to a patient's religion, world view and culture, is of utmost importance. This implies developing healthcare policies which stress the significance of adequate training of health care professionals "in communication skills and cross-cultural medicine" (Jotkowitz, Glick & Zovotofsky 2010b) and therefore approaching patients holistically, giving considerable attention to their (cultural) background, life stories and religious convictions, which may have a vast impact on concrete medical decision-making. Given the increasingly multicultural and multi-religious

outlook of contemporary Western societies, this is a huge but indispensable challenge, as this undoubtedly contributes to providing optimal care.

The findings of the study should be viewed against the backdrop of some methodological considerations. Firstly, the sample size is rather small, yet consistent with the method of data analysis, as theoretical saturation was reached. Despite the important contribution of this exploratory in-depth study, we acknowledge that in large-scale follow-up studies the topics and findings could be explored in greater depth. Further questions could be addressed: how or if gender plays a role in these issues, for example, would male adherents' attitudes differ from these findings; whether or not taking into account the specific character of the Antwerp Jewish community would change the outcome, and if similar research in other (Orthodox) Jewish communities abroad would lead to similar results; to which extent liberal but religious Jews' answers would differ from the attitudes of the secularized Orthodox participants; and whether situational research – among terminally ill Jewish patients – would lead to different conclusions. Secondly, to keep the study free from social desirability bias, confidentiality and anonymity were assured. Nevertheless, participants may have been reluctant to express personal opinions that they perceived as being in conflict with normative Orthodox Jewish and Hasidic values.

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[1] Interdisciplinary Centre for the Study of Religion and World View (Catholic University Leuven, Belgium). Website: http://theo.kuleuven.be/page/icsrw

8 Religion and Ethics at the End of Life. Elderly Jewish Women's Attitudes toward Withholding and Withdrawing Curative and Life-Sustaining Treatment

8.1 Introduction

During the last decennia multiculturalism and multireligiosity increasingly have become prominent characteristics of the Belgian society. During the same period biomedical technology has strongly evolved. As a consequence of this 'medical revolution' during recent years we are confronted with important new ethical questions and challenges. Despite Belgian society's cultural diversity, we notice that bio-ethical debates that overrun us today are often approached from the point of view of the large Western ideological traditions: the Christian tradition on the one hand, and the non-religious humanist tradition on the other hand. Hardly any attention is paid to the practices and attitudes of ethnic and religious minorities with regard to these bio-ethical issues.

Apart from the rather recent Muslim minority, Belgium houses since several centuries a Jewish community. Written evidence of the presence of this religious minority in Belgium dates back to the thirteenth century (Brachfeld 2000; p. 185; Abicht 2006, p. 26). Its population increased as a result of migration waves in the sixteenth, nineteenth and twentieth century (Schmidt 1994; Saerens 2000; Abicht 2006; Vanden Daelen 2008). Yet, it decreased drastically due to the atrocities committed against Jews during the Second World War (Saerens 2000; Vanden Daelen 2008). Today an estimated 40.000-50.000 Jews live in Belgium. The two largest Jewish communities are found in Brussels and Antwerp. In contrast to the larger community in Brussels, which consists of secular, liberal as well as Orthodox Jews, Antwerp Jewry is essentially Orthodox (Abicht 2006, pp. 371-410). The estimated 15.000-20.000 Jews in Antwerp belong to one of the following Orthodox communities: Machsike Hadas, Shomre Hadas or the Portuguese community. Orthodox Jews live mainly concentrated in the neighborhood of Antwerp's Central Railway Station and its famous diamond quarter. Despite the community's Orthodox character, it is not homogenous: apart from Hasidic (± 25%) (Gutwirth 2004, p. 31) and non-Hasidic Orthodox Jews (± 40%) secularized Orthodox Jews (± 35%) live in Antwerp as well. In contrast to Orthodox Jews, who follow the stipulations of Jewish law (strictly), for secularized Orthodox Jews being Jewish has little or any religious significance. Although being members of the Orthodox Jewish community, which provides them facilities for performing rites of passage, their Jewishness is understood on a cultural and ethnical level.

It is obvious that all participants of the Belgian society, religious minorities included, are confronted with bioethical issues. Therefore, as bioethical challenges come to the fore more often, Jews' voices on the matter should be included in the social debate. Being aware of this lacuna, an explorative qualitative empirical research was performed in the Orthodox Jewish community of Antwerp, aiming to explore elderly (age 60-75) Jewish women's attitudes on (forgoing) curative and life-sustaining treatment and the interplay with their religion and world view.

8.2 METHODS

From June 2008 until January 2009 23 semistructured in-depth interviews were conducted with a purposive sample of elderly (age ≥60) Jewish women in Antwerp (Belgium) concerning their religious convictions and practices and their attitudes toward ageing, illness, death and treatment decisions in advanced disease. As the Orthodox Jewish community reveals an internal diversity, Hasidic, non-Hasidic and secularized Orthodox Jewish women were interviewed in their home. The interviews were conducted in Dutch, following a Grounded Theory methodology (Glaser & Strauss 1967; Strauss & Corbin 1998), making use of a semistructured topic list. With regard to religion questions were asked about six dimensions of religion – the experiential, ritual, intellectual, consequential, ideological and social dimension – partially based on the multidimensional religiosity measurement model of sociologists Glock and Stark (1966). Attitudes toward end-of-life decisions were explored making use of hypothetical cases that were formulated on the basis of the typology developed by Broeckaert and the Flemish Palliative Care Federation (2006; Broeckaert 2008; 2009b). The interviewees were also asked to provide some demographic information about themselves. With the respondents' consent, the interviews were recorded. On average each interview took 99 minutes. Data collection continued until theoretical saturation was reached, i.e. when no new elements and insights came forward from further interviewing. After an interview had been conducted it was transcribed verbatim and anonymized making use of pseudonyms. Next, the interview was codified and analyzed following Grounded Theory methodology. By adding codes to the data and through constant comparisons, key concepts were identified in the interviews and categories were systematically generated and interrelated. For the data analysis MAXQDA 2007 was used. While data collection and analysis progressed, findings of the study were regularly discussed with the research supervisors. As this article focuses on the attitudes of elderly Jewish women toward (forgoing) curative or life-sustaining treatment, only these results will be presented. Special attention will be paid to the interaction between religion and ethics: in which way do religious convictions and practices influence attitudes toward (non-)treatment decisions and refusal of treatment?

Choices with regard to curative and life-sustaining treatment constitute one of the major categories of treatment decisions in advanced disease in the typology of Broeckaert (2008; 2009b; Broeckaert & The Flemish Palliative Care Federation 2006). Three kinds of decisions belong to this category: (1) continuing or initiating a treatment aimed at recovery or life sustainment; (2) withdrawing or withholding a treatment which is no longer considered to be meaningful or effective (non-treatment decision); (3) withholding or withdrawing treatment because the patient refuses treatment (refusal of treatment). For each of these subcategories hypothetical cases, mentioned in the box below, were presented to the interviewees.

Initiating or continuing a curative or life-sustaining treatment

There exists a cancer treatment that may prolong life with a few weeks. This treatment has many negative side-effects. Should a physician opt for this treatment?

Non-treatment decision

An unconscious patient is artificially kept alive (respirator, artificial nutrition and hydration). The patient is in a deep and irreversible coma. Should the devices be switched off so that the patient dies? Who should decide about that?

Refusal of treatment

A physician has told his/her patient that chemo therapy may cure his/her cancer. Has the patient the right to refuse this treatment, even if he/she knows he/she will die soon if no treatment is administered?

8.3 Results

8.3.1 Participants' background and religious identity

The 23 participants were aged between 60 and 75 years, with a mean of 65 years. (The ancestors of) 12 respondents lived in Belgium before the Second World War and 11 respondents migrated to Belgium afterwards. Participants were born in Belgium (n=13), the Netherlands (n=2), Switzerland (n=3), Indonesia (n=1), Uzbekistan (n=1), France (n=1) and Israel (n=2). Mother languages included Yiddish (n=6), Dutch (n=5), French

(n=4), English (n=2), German (n=2), Hebrew (n=1), Dutch-French (n=2) and Polish-Yiddish (n=1). The overwhelming majority of the respondents was polyglot, mastering a total of between three and nine languages. 17 of them were married, 3 were divorced and 3 were widow. Orthodox (Hasidic and non-Hasidic) respondents had noticeably larger families (0-10 children) than secularized Orthodox Jewish respondents (1-4 children). All Orthodox participants lived in the neighborhood of Antwerp's Central Railway Station and the diamond quarter, in contrast to the majority of the secularized Orthodox respondents. 15 participants were Orthodox (6 Hasidic and 9 non-Hasidic) and 8 interviewees were secularized Orthodox. Huge differences in religious identity were found between secularized Orthodox and Orthodox Jewish women. While the majority of the secularized Orthodox Jewish respondents said to be not or indecisively religious, every Orthodox woman interviewed considered herself as religious or very religious.

8.3.2 Participants' attitudes toward withholding/withdrawing treatment

8.3.2.1 Initiating or continuing a curative or life-sustaining treatment

When presenting this case secularized Orthodox Jewish interviewees emphasized the patient's right of self-determination: the physician does not decide to administer the treatment, the patient does. A similar opinion was found among two non-Hasidic Orthodox respondents.

> When life is feasible and realistic and it's bearable for the patient, then he has to do the best he can. And when the patient says 'it's enough'. Well, then it's enough. C'est tout. (Leah)

The secularized Orthodox interviewees opposed medical paternalism and futile treatment. A patient's quality of life was considered to be an important element in medical decision-making. They reported that life can be prolonged if a patient wishes so and in humane, bearable circumstances. The patient's autonomy was less emphasized by the Orthodox respondents. The Hasidic women were more concerned about the importance of preserving life. According to them, nearly every effort has to be made to extend life.

> Normally he has to, from a Jewish point of view, because for a Jew every single day is important, every single hour, every single minute, every single moment he can do something which God asks to do. So, every moment of life is important. And he has to do everything to live. (Nechama)

Nevertheless, Chaya made a distinction between extending viable life and extending a dying process. For her, a moribund's suffering may not be prolonged.

> Ah, saving a life as long as that man is in a good condition. I'm not talking about dying people who can no more, (…). But in case someone is in a good condition, and young, certainly, he has to do what he can to save life. (Chaya)

Whereas most Hasidim emphasized the absolute importance of extending life, not all non-Hasidic Orthodox Jewish women agreed that life has to be extended at all expenses. For Sarah, Tzippa, Judith, and Miriam life has (preferably) to be prolonged. Yet, Miriam referred as well to a person's autonomy; in the end she suggested to seek rabbinic advice in this case. According to Tamar a patient's autonomy has to be respected. For a few respondents – Esther, Norah, Danielle, Elizabeth – the context and circumstances of a case have to be taken into account.

> It depends. When that person has a few more good weeks, then I agree. But if he suffers and he's in great pain, then I don't agree (Esther)

For Elizabeth, a non-Hasidic Orthodox interviewee, life must not be prolonged at all costs. She considered prolongation of life in the hypothetical case futile and mere prolongation of suffering.

> I said once 'if I'd be that ill, I would not choose such hard treatments'. So, for me, it's not necessary. […] Personally I don't like suffering. […] When I see what people go through, then I don't know whether I would have the courage, I personally wouldn't have the courage to do it. (Elizabeth)

Strikingly, three Orthodox Jewish respondents associated non-treatment with shortening life, which they considered – in line with Jewish law – absolutely forbidden.

> Yes, again we have to ask a rabbi, but normally you want to prolong life, it's important. […] We would probably ask the rabbi. But it's not possible to say it the other way round, I don't do it, when knowing that it shortens life. We are not allowed to shorten life. (Sarah)

8.3.2.2 Non-treatment decision

Five secularized Orthodox Jewish women agreed with switching off medical devices which keep an unconscious patient artificially alive. According to them close family

members can make the decision to end this inhumane situation, in close consultation with the physician and after a period of careful consideration.

> But someone in a coma, who doesn't hear anymore, who doesn't see, who doesn't... nothing, only lying there. I think that at that moment, euh, the decision to keep such a patient in this condition is even harder than to stop it. But then you should probably first for one or two years consult different doctors and, and professors and so on, in order to see if something can be done about it, to be sure for 100% that you do not let someone pass away who still has a chance to live. (Ruth)

Whereas according to them keeping the patient artificially alive is inhumane and causes suffering for the close family, secularized Orthodox participants Josephine and Joanna on the other hand considered it inhumane to withdraw life-sustaining medical devices. Alternatively, according to Josephine, starting life-sustaining medical treatment initially should carefully be thought over.

> But I could never imagine that, if a doctor says 'she's connected with a machine, she's artificially fed, she's given this, she's given that, now you have to choose whether I switch it off immediately or not'. No, that's a bit inhumane, I think. (Joanna)

All Hasidic respondents strongly disapproved of this case, as this decision would imply a human intervention in God's plan with humanity. According to them only God is the author of life and death. Among these interviewees switching off life-sustaining medical devices was seen as a life-shortening act. They reported that there is always hope, as God moves in a mysterious way.

> From a Jewish point of view not, because we never know whether he returns. It happened in our family last week. (...) The doctors couldn't believe it. He returned and now, thank God, he's back home, and he is, he functions. So, that can happen. We never have the right to judge, who can live, who cannot. That's always heavenly work. (Nechama)

Among the non-Hasidic Orthodox women an intermediate position was found. Most respondents were opposed to switching off life-sustaining medical devices, as for them this would mean a transgression of Jewish law and an intervention with God's will.

> -We are not allowed to take it away. And this was my battle in that hospital. [...] And she, my mother, had to be insufflated with all kinds of different machines. And she did it.
> -She was in a coma?
> -Yes. [...] That's my choice. Alright, now you will say 'there are people who do not make it', but that's also God's choice. But we cannot tolerate that. (Danielle)

Still, in contrast to the Hasidic interviewees, among the non-Hasidic Orthodox participants, openness for this non-treatment decision was found. Some (Tamar, Judith and Miriam) mentioned that the context and circumstances of each case have to be carefully taken into account; thus they did not *a priori* reject withdrawal of life-sustaining treatment in the hypothetical case. Miriam stated that in this case she would seek rabbinic guidance. Tamar and Judith were sure withdrawal of medical devices in case of an unconscious patient is prohibited by Jewish law. Still, in case she would end up in the situation described in the hypothetical case, Tamar wouldn't want to be kept alive.

> I would want this for myself if I would end up like this. But it's not allowed, it's not allowed. It's a pity. (Tamar)

Norah and Esther explicitly approved of the presented case, as for them patient and family members have to be freed from the inhumane situation of suffering, caused by this irreversible coma.

> I am in favor of it. According to the Jewish law it's not allowed. But for me it is. Because I think that, that person's life is useless to him. And for the family, it's a, it's, it's terrible to stay near the bed and to wait until he dies. For me that's awful. (Esther)

Among the Orthodox women, both Hasidic and non-Hasidic, reference was frequently made to seeking rabbinic advice.

> No that's not allowed. But let's say, I'm not yet in such a situation. And I hope I will never be in such a situation. But then I will, and should I hesitate, I will consult a rabbi. (Chanah)

8.3.2.3 Refusal of treatment

Again, the secularized Orthodox sample emphasized the patient's absolute right of self-determination and proclaimed the right to die.

> Yes, I totally agree with that. I think everyone has the right to live or not, to bear illness or not. [...] For me you have to be free, free in choosing a physician, free in choosing treatment. (Ruth)

The Hasidic women left less room for personal freedom of choice. They reported that basically one should follow Jewish law and choose for prolongation of life.

> -That's very difficult. That's a question for an authority. Normally he has to do everything to stay alive.
> -Do you have a personal opinion on this? May a patient refuse this according to you?
> -Normally not, normally not. If you can... But there are people who react negatively when they hear 'chemo', as they know the side-effects. (Nechama)

Yet, they stated that in certain circumstances (and in consideration with a rabbinic authority) treatment can be refused. After all, they said, a patient cannot be forced. Three Hasidic respondents referred to a patient's autonomy, although, they stressed, basically a Jew is obliged to choose for recovery.

> -That's his wish. (...) So if he, if the doctors say 'if you follow this, then you have this chance or maybe 100% chance', yes, then he still is free to choose. But there are also people who are free to throw themselves under a tram or euh.
> -But euh earlier you said that that, euh, basically each moment of life is...
> -Yes, OK, but you cannot force the person, the patient. (Suzannah)

In the non-Hasidic Orthodox sample the importance of a patient's personal freedom was less toned down. The opinion of two respondents, Elizabeth and Esther, was similar to the viewpoints of the secularized Orthodox Jewish sample.

> -According to me, yes. It's first and foremost the patient who decides.
> -So, according to you a patient has the right to...
> -Yes, absolutely. (...) I have seen someone who was given a kind of chemo and it really troubled him. He really suffered, and then I can imagine that he

> would refuse the next cure. With so much pain everywhere and so much misery. Ho, I think that's his right. (Esther)

The other non-Hasidic Orthodox respondents, as well, respected the patient's individual freedom of choice. This is clear from the distinction they made between what they would want for themselves in that situation and the autonomy of the patient in the case. Moreover, a few respondents contrasted their personal opinion with the regulations of Jewish law.

> Yes, it's his… Yes, it's his… It's stupid, it's stupid, it's stupid. If he really can recover, and really, I will try everything, should that be someone who I know well, I will try everything to convince him to do it. But it's his life, he may choose. (…) That's not helping someone, not helping someone to die. He chooses that he doesn't want to be helped. He's right. (Tamar)

> A patient, basically, if he wants to do it well, he has to do the chemo. But he can choose, yes. (…) Yes, I do think that we cannot decide. We cannot decide 'now I have lived enough'. (…) It's not 'it was enough for me', that's not in my hands. (Tzippa)

Other respondents in the non-Hasidic Orthodox sample reduced the emphasize on the right of self-determination by stressing religious instructions. They said that their opinion coincided with these regulations. As was the case with the Hasidic sample, these non-Hasidic Orthodox respondents seemed to suggest that their opinion was *the* Jewish view.

> - I do, but probably according to the law it will, they would say 'if she's alive, she's alive'.
> -But what would be decisive for you? […]
> - If I should have to decide?
> - Yes, if you should have to decide.
> -The rabbi.[…] Follow the law.
> - Although you think that…
> - Yes, yes, yes. Because what I think is not, is not enough to, to. These are my personal feelings, but it's not what the law says. I would do what is decided by the rabbi or explained by the law. Absolutely. (Sarah)

Orthodox Jewish respondents, both Hasidic and non-Hasidic, regularly recommended to consult a rabbi in this situation. Again, this seemed to limit the patient's right of self-determination. Indeed, (most) Orthodox Jewish respondents deemed a rabbi's advice binding.

> This I tell you as an Orthodox woman: for this we consult our rabbis. We do not decide anything. (Danielle)

8.4 Discussion

8.4.1 Inter- and intra-sample diversity

The results reveal an inter-sample as well as an intra-sample diversity concerning attitudes toward choices with regard to curative and life-sustaining treatment. Samples that revealed most internal unanimity were the secularized Orthodox sample on the one hand and the Hasidic sample on the other hand. Situating these samples on an axis, the secularized Orthodox sample can be situated on the left – stressing the right of self-determination and quality of life – and the Hasidic sample on the right – stressing the sanctity of human life. The non-Hasidic Orthodox sample occupies an intermediate position, as different voices – even personal opinions which deviate from Jewish law – are heard.

All secularized Orthodox Jewish respondents considered withholding a curative or life-sustaining treatment which may prolong the life of a cancer patient with a few weeks, yet entailing many negative side-effects, as permissible. This stands in sharp contrast with the Orthodox – both Hasidic and non-Hasidic – interviewees' attitudes, predominantly stressing the importance of preserving life. Yet, some non-Hasidic Orthodox respondents' views were less clear-cut, stressing the concern for individual patients' context and circumstances.

With regard to withdrawing devices in the case of an unconscious patient artificially kept alive, in the secularized Orthodox sample no unanimity was found. Nevertheless, in this sample a positive attitude toward the option to withdraw treatment in the hypothetical case predominated. In contrast, most Hasidic and non-Hasidic Orthodox interviewees were opposed toward withdrawal of treatment in the presented case. Yet, in the non-Hasidic Orthodox sample a minor positive openness toward withdrawal in the hypothetical case was found.

8.4.2 Distinction between withholding and withdrawing?

Remarkably, the majority of the interviewees made no significant distinction between withholding and withdrawal of treatment in the presented cases. The Hasidic respondents for instance treated both cases on equal terms. Similarly, Wenger and Carmel (2004) found that very religious Jewish physicians in Israel made hardly if any distinction

between both decisions, as for them offering life-sustainment prevailed. And yet, *halacha* – Jewish law – seems to differentiate between both (Rosner & Tendler 1997, p. 54; Ravitsky 2005, pp. 415-417; Jotkowitz, Glick & Zovotofsky 2010a). Still, it should be noted that there is disagreement between Jewish scholars on the matter. For some both are acts of omission, in which nature is allowed to take its course. For others, withdrawal of treatment is an act of commission, and thus problematic, as it is equal to active termination of life (Flancbaum 2001, pp. 289-298; Zemer 1999, pp. 351-356). In order to meet rabbinic objections to withdrawal of life-sustaining treatment, the Israeli Dying Patient Law (2005) acknowledges a moral distinction between withholding and withdrawing treatment. As such, the use of timers on ventilators was introduced, which turns continuous ventilatory support into a non-continuous treatment, and thus transforms discontinuation of mechanical ventilation from a (problematic) act of commission into an (unproblematic) act of omission (Barilan 2004; 2007; Ravitsky 2005; Steinberg & Sprung 2007; Jotkowitz & Glick 2009a). In this way secular and religious camps of the law's committee were reconciled (Schicktanz, Raz & Shalev 2010). Still, despite the reached consensus, Jotkowitz and Glick (2009a) show that this (moral) differentiation – refraining from treatment *versus* interrupting (continuous) treatment – remains controversial.

Among our non-Hasidic Orthodox respondents more openness was found toward withholding than withdrawal. Elizabeth, a non-Hasidic Orthodox Jewish woman who approved of withholding treatment in the presented hypothetical case, strongly disapproved of withdrawing treatment, as she considered it equal to active termination of life. While Danielle, another respondent in this sample, was not *a priori* opposed to withholding treatment in the presented case, she strongly disapproved of withdrawing medical devices in the case of an unconscious patient, referring to a personal experience. Two secularized Orthodox women considered withdrawal of treatment inhumane, whereas they did not oppose withholding treatment in the presented case. Similarly, in other studies (in health care settings in Israel) lower acceptance and/or frequency of withdrawing than withholding treatment was found, which was ascribed to the influence of *halacha* on Israeli law and culture (Eidelman *et al.* 1998; Soudry *et al.* 2003; Sprung *et al.* 2007b; Ganz *et al.* 2006). This impact of Jewish religious teachings and (Orthodox interpretations of) *halacha* is considerably reflected in the 2005 Israeli Dying Patient Law (Barilan 2007), which underlines the doctor's duty to preserve life (Schicktanz, Raz & Shalev 2010; Shalev 2010) and differentiates clearly between refraining from medical therapy (which is allowed) and interrupting continuous treatment, such as artificial respiration and feeding (which is not allowed) (Jotkowitz & Glick 2009a; Schicktanz, Raz & Shalev 2010). Christakis and Asch (1995) found that Jewish physicians in Pennsylvania were less willing to withdraw life support, yet more willing than their Catholic colleagues. In other studies as well a comparison was made with Catholics and adherents of other religions (Society of Critical

Medicine Ethics Committee 1992; Sprung *et al.* 2003). Ejaz (2000) found that elderly Jewish people in Cleveland were more favorably disposed toward life-sustaining treatment than Christians.

8.4.3 Influence of religious convictions

The opposition against withdrawing and withholding treatment among the Hasidic and most non-Hasidic Orthodox interviewees is understandable in light of their religious convictions. In fact, their arguments against both treatment decisions are exclusively religious. In reaction to both hypothetical cases – on withholding and withdrawing – the importance of preserving and prolonging life was stressed. Indeed, in the Jewish tradition the duty to save and preserve life (*pikuah nefesh*) is central (Jakobovits 1975, pp. 49-52; Glick 1999, pp. 43-53; Rosner 1986a, p. 12). Especially withdrawal of treatment was explicitly seen by these interviewees as a life-shortening act, which is contradictory with God's sovereignty in the domain of life and death. Similarly, elderly Jewish participants in the study of Leichtentritt and Rettig (1999) made no distinction between letting die and shortening life and argued against human control over life and death decisions. Indeed, our Orthodox interviewees were religiously observant Jews, who follow God's laws. As they considered God to be almighty and omniscient – in contrast to human beings' limited knowledge – they expressed the view that everything – life, death, illness, healing etcetera – is in God's hands. After all, they believed that God has a meaningful plan with the world and with humankind, which is for the good of man. So, human beings should put complete trust in God. This ultimate trust in God is expressed through the (strict) observance of Jewish law, articulation of God's will for humanity. After all, cultivating a faithful relationship with God guarantees reward in this life or in the world to come. As this orthodoxy and, especially, orthopraxis – performing good deeds – is very central for Orthodox Jews, every decision has to be taken in accordance with Jewish law. Therefore, in case of religious or ethical dilemmas, it is recommended to consult a rabbi, who's considered to be a specialist of Jewish law. Similarly, Coleman-Brueckheimer, Spitzer and Koffman (2009) noticed a high degree of rabbinic involvement in treatment decisions among strictly Orthodox breast cancer patients, to make sure that their actions accorded with God's will. Given that the Torah makes clear that every single moment of human life should be cherished, for the Orthodox participants life-prolonging treatment decisions should be made. And God takes care of the rest.

> Yes, in our faith, yes, we fight for life. (...) Every second, because only God decides. If God has decided that that person has to pass away, either he will

> die before he starts the treatment, either during the treatment. It was of no avail. But we have done everything. (Leyla)

Thus, an interplay between their ethical attitudes and religious convictions was found. Similarly, previous studies among (Jewish) elderly showed a positive correlation between (the degree of) religiosity and the will to preserve life (Carmel & Mutran 1997; Leichtentritt & Rettig 1999; Ejaz 2000). Ejaz (2000) found that Jewish elderly with a stronger reliance on God were more likely to agree with life-sustaining treatment. A similar conclusion is drawn from Wenger and Carmel's (2004) study among Jewish physicians in Israel. In contrast, an earlier study of Carmel (1996) found no effect of physicians' religiosity on life-sustaining attitudes and behavior. From our study we found that women who have faith in an almighty God who determines everything are more likely to disapprove of the decision to withhold or withdraw a life-sustaining treatment when they consider this as intervening with Jewish law, i.e. God's will – which commands Jews to preserve and prohibits them to shorten life. These interviewees saw withholding and withdrawing treatment as an intervention with God's plan who is supposed to be the only author of life and death. For them, in the hypothetical cases the physician illegitimately enters a domain which is not his: the task of a physician is to save life, not to give up life and certainly not to shorten it.

Noticing this, it is understandable why a few religiously observant (non-Hasidic Orthodox) interviewees who expressed faith in an almighty God, did approve of withholding treatment. For them, a physician who decides to forgo further treatment in case of a cancer patient who has only a few more (painful) weeks to live does not enter into God's domain of life and death, as this decision has nothing to do with shortening life. Further treatment is considered futile and a prolongation of the patient's suffering. Withdrawal of treatment in the presented hypothetical case, on the other hand, was considered (by all non-Hasidic Orthodox as well as Hasidic women) as an intervention with God's sovereign authorship over life and death. Yet, this did not prevent some non-Hasidic Orthodox interviewees to have sympathy for physicians and families who decide otherwise. In the end, human beings must not judge other people's actions, God is the ultimate Judge.

The interplay between ideological convictions and ethical attitudes also came forward among the *proponents* of withholding treatment and withdrawing medical devices in the hypothetical cases. Arguments in favor of withholding/withdrawal were: the concern about the quality of a patient's life and the general well-being of the patient and his/her family and the importance to take a patient's (and his/her family's) right of self-determination into account. Non-Hasidic Orthodox respondents Esther and Norah and all secularized Orthodox interviewees strongly disapproved of futile treatment – only

Josephine and Joanna were opposed to withdrawal of life-sustaining devices in the case of an unconscious patient, as they considered this an inhumane decision. The point of view of Norah and Esther and of the secularized Orthodox Jewish respondents is understandable taking their religious and ideological convictions into account. The majority of the secularized Orthodox Jewish sample said to be not or indecisively religious. Only two respondents considered themselves religious. Yet, none of them believed that God is almighty. All secularized Orthodox respondents were of the opinion that God does not play a role in disease or death, given that for them either he does not exist or he is a good God who is not responsible for everything that happens in the world. These interviewees considered illness and death as merely profane facts. Thus, when discussing non-treatment decisions God did not come to the fore. Moreover, as their Jewishness has little or any religious connotation, the regulations of Jewish law were rarely if ever mentioned. Frequently referring to the importance of human beings' right of self-determination and quality of life, (non-)treatment decisions were discussed on a profane level, without taking note of a heteronomous, transcendental reality.

In their reaction on the hypothetical case of refusal of treatment the autonomy of the patient was mentioned in the three samples. Apart from the stress on self-determination the main pro-refusal argument was the concern for a patient's general (physical and psychological) well-being. Yet, in contrast with the secularized Orthodox interviewees, who considered a patient's autonomy as absolute, this stress on the right of self-determination was weakened among the non-Hasidic Orthodox and even more among the Hasidic participants. According to them, preferably treatment should be chosen. Again, contra-refusal arguments were exclusively religious: the concern for leading one's life in conformity with Jewish law, i.e. the expression of God's will, which commands to preserve life. Again, deciding not to be treated was considered as transgressing this commandment and thus intervening with God's plan, which also includes the determination of a person's time of death.

8.4.4 Limitations of the study

The findings of this study should be viewed against the backdrop of some methodological considerations. First, the sample size is rather small, yet consistent with the method of data analysis, as theoretical saturation was reached. Despite the important contribution of this explorative in-depth study, we acknowledge that in large-scale follow-up studies the topics and findings could be explored in greater depth. Second, to keep the study free from social desirability bias, confidentiality and anonymity were assured.

Nevertheless, participants may have been reluctant to express personal opinions that they perceived to be in conflict with normative Orthodox Jewish and Hasidic values.

8.5 Conclusions

The research results of this first explorative study in Antwerp, Belgium, on the attitudes of elderly Jewish women with regard to withholding and withdrawing curative and life-sustaining treatment, first, endorse the heterogeneous character of the Orthodox Jewish community in Antwerp. Samples that revealed most internal unanimity with regard to the ethical dilemmas presented were the secularized Orthodox and the Hasidic sample. Secularized Orthodox interviewees were predominantly concerned about a patient's absolute autonomy and his/her quality of life. In the Hasidic sample, on the other hand, the importance of preserving and prolonging life prevailed. The non-Hasidic Orthodox sample occupied a rather intermediate position, as among these interviewees divergent voices were heard.

Second, among Hasidic women no difference of opinion was found with regard to withholding and withdrawal of life-sustaining treatment. On the other hand, in the non-Hasidic Orthodox sample, a few interviewees did distinguish regarding the acceptability of both treatment decisions. Their (rather) permissible attitude toward withholding treatment – which was considered futile and mere prolongation of suffering – shifted to an outright denunciation of withdrawal of medical devices in the case of an unconscious patient, as it was seen as a life-shortening (prohibited) act.

Third, this study shows an interplay between religion and ethics. Whereas interviewees who had no faith in a transcendental, almighty reality were more likely to emphasize a patient's absolute right of self-determination, respondents who had faith in an almighty, omniscient and good Creator and Governor of the world were more likely to put complete trust in God, who encourages Jews to take care of life, as only in His hands is the moment of death. One's image of ultimate reality, to what extent one agrees with the essentials of the Jewish religion and the perception of withholding and withdrawal as a (il)legitimate human intervention, seem to influence one's attitudes toward withholding and withdrawing curative or life-sustaining treatment.

9 Conclusion

In this part, we elaborated on Jewish perspectives on ethical dilemmas in end-of-life care. Apart from reviewing normative Orthodox, Conservative and Reform Jewish views on death, medicine and illness and on particular treatment decisions at the end of life, such as organ retrieval from brain-dead donors, euthanasia, and withholding and withdrawing life-sustaining treatment, part 1 was devoted to a presentation and discussion of the findings of our qualitative empirical study which was conducted in the Orthodox Jewish community of Antwerp (Belgium).

The chapters reviewing normative Jewish opinions on treatment decisions at the end of life (chapter 3, 4, 5), were meant to gain insight into the way Jewish ethical reasoning functions, specifically in contemporary moral dilemmas in health care. They functioned as a first (necessary) acquaintance with Jewish medical ethics, before digging into the actual ethos found among a particular group of Jews living in Antwerp (Belgium) today. Chapters three, four and five showed that Jewish ethical reasoning is text-centred, consisting of interpreting the Jewish textual tradition, and seeking precedents in it, which might illuminate the case at hand. The way in which rabbis or *poskim* (specialists of Jewish law) judge a similar case, may differ widely, due to their divergent ways of applying *halachic* texts and concepts to the case, and given the diverging degrees of authority they ascribe to (interpretations of) *halacha.* (Jewish law). We showed that, in dealing with present-day ethical queries in end-of-life care, rabbis draw on a common arsenal of values, principles and texts, but these are not necessarily shared by all at all times, and interpreted or used in a similar way.

As such, the chapters showed that heterogeneity is an essential characteristic of Judaism. Judaism lacks a central coordinating authority which would proclaim definitive *halachic* rulings or official Jewish statements. Therefore, Jewish ethical reasoning gives evidence of a 'heterogeneous specificity', referring to the fact that *halacha* constitutes the central focus of Jewish ethics, but indicating at the same time that moral conclusions reached on the basis of *halacha* may be divergent. We mentioned that this pluralism may exceed 'denominational boundaries'. Thus, Judaism is not only diverse in terms of consisting of several branches or denominations, in its different movements uniformity is also lacking.

Abstract, theoretical *halachic* considerations on actual ethical dilemmas in end-of-life care (more specifically euthanasia and withholding/withdrawing life-sustaining treatment), were the focus of chapters four and five. It is important to acknowledge, and we stressed

this frequently in the previous pages, that Jewish (medical) ethics applies a bottom-up approach, starting with concrete questions of individual Jews. Although, normative Orthodox, Conservative and Reform Jewish views are found in literature and on the Internet, often, patients' ethical questions are considered on a case-by-case basis by competent rabbinic deciders. Therefore, speaking of one unanimous Jewish opinion on a particular ethical query is nonsense.

In the first chapters of this part, it was regularly shown that world view and ethics interfere. Chapters six, seven and eight focussed on an examination of the actual ethos of a particular group of Jews living in Antwerp (Belgium), namely elderly Jewish women (age $\geq$ 60), being either a) Hasidic, b) non-Hasidic Orthodox, or c) secularized Orthodox. In these chapters particular attention was paid to the central research questions of the doctoral dissertation: (1) what are the attitudes of elderly Jewish women (age $\geq$ 60) living in Antwerp (Belgium) toward ethical dilemmas which may occur in contemporary end-of-life health care; (2) to what extent does the participants' ethos correspond with or deviate from Jewish standpoints found in normative literature, and very tentatively (3) whether there is an interplay between specific religious Jewish beliefs and moral attitudes, and which facets of religiosity play a major role.

Quite evidently, upon reconstruction of our participants' way of thinking, a link between their Jewish beliefs and practices and their ethical attitudes was found. Predominantly, among Orthodox Jewish participants, every action which was perceived as active termination of life was rejected, because of their emphasis on the sanctity of human life. Secularized Orthodox Jews were more likely to stress quality of human life and human autonomy, and thus, to accept active termination of life.

While this sounds quite evident, our empirical study tentitavely showed that the interplay between religion and ethics might be much more complex. We found religious Jewish women who approved of euthanasia, despite their faith in God. Noting this, we discovered that not so much being Jewish, but ***what*** our interviewees ***believed*** and their ***image of God***, had an important impact on their moral attitudes. In our empirical findings we, first, discovered that interviewees who did not have faith in God or an ultimate reality, were more likely to underline a person's absolute right of self-determination with regard to life and death. Life, death, illness and health were not associated with God or a transcendental reality, but were interpreted on a purely profane level and seen as mere coincidence. These interviewees were very tolerant toward active termination of life and withholding and withdrawing of life-sustaining treatment. Second, participants who had faith in an almighty, omniscient God, were more likely to put human beings' fate in God's hands. They believed that God created the world, and that He governs human beings' life and death. Interpreting life, health, illness and death on a transcendental level, they were more likely to oppose

human intervention in the realm of life and death. As such, they took a very negative stance toward every act which they perceived to be active termination of life: euthanasia, assisted suicide, and often also withholding and withdrawal of treatment. Third, irrespective of being (non-)Hasidic Orthodox, or secularized Orthodox, interviewees who had faith in God, but who refused to believe in God's almighty power with regard to life, death, illness and health, were more likely to stress human beings' right to decide about the end of their life. God would not want human beings to suffer, they argued, thus leaves room for ending their lives in a situation of unbearable suffering.

Despite its small-scale, exploratory character, we believe that our (empirical) study has important implications for contemporary health care. First, it can help to fill in a lacuna in current academic, social and political debates in Belgium on pressing ethical queries related to health care, such as euthanasia, which are dominated by Christian and non-religious humanist perspectives, and in which voices of important religious minorities, for instance Jews, are lacking. Second, our study may help health care professionals to gain insight in specific issues related to the treatment of Jewish patients. Today, it is recognized that it is essential to take a holistic approach of patients. Health care professionals should not only pay attention to the physical aspect of patients, but the social, psychological and spiritual aspect should also be addressed. Giving attention to the religious identity of a patient should not only be restricted to offering spiritual counselling or answering ritual needs of patients and their families. Our study showed that patients' religious beliefs have much more implications for the provision of optimal care. It demonstrated that religious convictions are involved in very concrete medical decision-making. At the same time, Jewish views on for instance euthanasia cannot be brought under the same heading, which constitutes an additional challenge. In hospitals where nurses and physicians are likely to meet Jewish patients, sufficient attention should be paid to thorough training. Time should be spent to acquaint health care professionals with the characteristics *and* diversity of the Jewish tradition, and with Jewish sensibilities. They should be made aware of Orthodox Jews' general hesitance toward quality-of-life judgements, and the delicacy of subjects like active termination of life (in our study we noticed that this is not only related to central religious convictions, but also to the history of Jewish persecution), and they should be made conscious of the possible involvement of rabbinic authorities in the medical decision-making process.

At the same time, attempting to introduce fixed guidelines regarding treatment of Jewish patients in these hospitals, would do harm to the essential diversity in Judaism. Religious Judaism has different branches, and an important part of Jews world wide is secularized. As such, having thorough knowledge of Judaism is not sufficient in order to provide optimal care. In order to avoid ignorance of patients' needs, health care

professionals should realize that apart from being Jewish, Jewish patients have different religious ideas, life-stories, backgrounds and contexts which influence their way of coping with illness and concrete medical decisions. As such, they should be sufficiently trained in communication competencies and skills to improve religious sensibility in general.

Throughout the chapters of this first part, we noticed that Judaism is a religion of life. Chapter two explained that, while taking a very realistic attitude toward death, in Judaism eventually life prevails. Great reverence for life was a leitmotiv throughout this first part. And yet, simultaneously the inner-Jewish heterogeneity – reflected in the Jewish folk saying "two Jews, three opinions" – was regularly stressed. We found that there are multiple Jewish ways of coping with illness and medicine, which are significantly influenced by religious convictions one holds on to. However, the exploratory, tentative character of the study, the specificity of the Jewish study population and the small-scale nature of the study must be kept in mind. The tentative conclusions which were drawn out of the small-scale study, may function as a basis for further large-scale empirical research. In the next part, we examine moral attitudes and religious convictions (and the link between both) of adherents of another Semitic religion prominently present in Belgian society: Islam.

PART 2:

ISLAM & ETHICAL END-OF-LIFE DILEMMAS

10 Introduction to Part 2

The second part of the doctoral dissertation attempts to throw a light on Islamic views on ethical dilemmas in end-of-life health care. This part examines (1) what are the attitudes of elderly Muslim women (age ≥ 55) living in Antwerp (Belgium) toward ethical dilemmas which may occur in contemporary end-of-life health care, (2) to what extent the participants' ethos corresponds with or deviates from Muslim standpoints found in normative literature, and very tentatively (3) whether there is a link between specific religious (Islamic) beliefs and the way ethical questions at the end of life are dealt with, and what precisely constitutes this interplay. In a lot of Western European countries, Islam has become the second largest religion. In comparison to Judaism, which has a centuries-old presence in Belgium, the emergence of Islam in the country is rather recent. The systematic arrival of Muslims in Belgium started in the late fifties-early sixties of the twentieth century. After the mining disaster in Marcinelle in 1956, labour migration from Italy ended. In search for new workers for its mining industry and other (industrial) sectors, Belgium established bilateral agreements with the governments of Morocco and Turkey. In these countries male 'guest workers' were recruited, who migrated to Belgium. Most of them were of very humble descent, uneducated and illiterate. Turks originated mainly from small villages and rural areas, predominantly situated in the central Anatolian provinces. Afyon, and particularly the district of Emirdag, were very dominant in the migration of Turkish labourers to Belgium. Very important emigration areas in Morocco were the Northern provinces. A lot of first generation migrants originated from the region of the Rif, and particularly from the provinces of Nador and Al-Hoceima. These migrants had a rural background and usually their mother tongue was Berber. Another large group of Moroccan 'guest workers' migrated from other provinces situated in Northern Morocco (mainly Tanger, Tetouan and Oujda). Generally, these migrants spoke (Moroccan) Arabic and originated from urban areas. Apart from official migration via recruitment offices (mainly in Turkey), unofficial individual migration took place (especially among Moroccans). Often, (in particular among Turks) wives (and families) of the labour migrants stayed behind, since the labour migration was initially seen as temporary. Due to the changing (more permanent) character of their migration and Belgium's family reunification policy in the mid-1970s, they later joined their husbands. Ever since, the Muslim population in Belgium continued growing (Lesthaeghe 1997; 2000; Reniers 1999; 2000; Lodewijckx 2010).

Despite their visible presence in Belgium (today approximately 600.000), especially in large urban areas, Muslims remain rather absent in societal, academic and political debates, for instance on the acceptability of euthanasia. Even though normative Islamic standpoints with regard to euthanasia and other ethical queries in end-of-life care can easily

be found, for instance on the Internet, we considered it important to probe the attitudes of first generation migrants of Moroccan and Turkish origin, who settled in Belgium forty to fifty years ago, who grow old today, and hence might have increasing medical needs. Being part of a broader research programme of the Interdisciplinary Centre for the Study of Religion and World View (KU Leuven) on religion and ethics, this part of the doctoral project was a continuation of the study done by dr. Stef Van den Branden (2006), who examined Islamic Sunni views on treatment decisions at the end-of-life and who conducted face-to-face interviews with elderly first generation Moroccan men in Antwerp (Belgium). Seeing that an extensive review of normative Islamic views on the studied topic had already been undertaken by dr. Van den Branden, we did not assume it useful to elaborate on it in a separate chapter. Therefore, this part of our doctoral project tended to focus on the particular ethos of elderly first generation Moroccan and Turkish Muslim women in Antwerp. Through cofication of the face-to-face interviews, we aimed to enter into and reconstruct their religious views and way of thinking about specific moral dilemmas in health care. The chapters, which are conceived as articles suitable for publication in international scientific journals, focus on the findings of our exploratory empirical study. In the discussion section of the chapters we confront them with normative Islamic views with respect to the research topic.

In the first chapter (chapter 11) after this introduction, we discuss the perspectives of our sample on medicine, illness and suffering. This chapter wants to show that spirituality is an important dimension of patient care: it not only impacts on patients' ritual needs (such as prayer), but also on the way they deal with illness and suffering and very concrete medical decisions. The findings may be of particular importance for hospital chaplains, who might act as spiritual care references in the medical team, and hence might inform physicians and nurses on the ward about specific sensibilities and viewpoints of Muslim patients.

Chapter 12 reports on the attitudes of the research participants toward active termination of life. The findings show an important and complex impact of religion, specifically one's image of God, on attitudes toward active termination of life. Additionally, the chapter points to the danger of adopting a simplistic and non-nuanced approach of Muslim patients.

Chapter 13 deals with Muslim views on non-treatment decisions. Again, the empirical findings of our study among elderly Moroccan and Turkish Muslim women in Antwerp (Belgium) constitute the focus of the chapter. Relying on the results, the chapter shows that non-treatment decisions are not value neutral, and that medical futility decisions are double-levelled. We will argue that, in order to offer sincere and adequate context-sensitive care, clinicians must move beyond the level of physiologic effectiveness to the

level of meaning, paying genuine attention to a patient's value-system. All chapters address the central research questions, and draw tentative conclusions with regard to the link between religion and end-of-life ethics.

This part of our doctoral project set up a small-scale, exploratory qualitative empirical study in the Muslim Moroccan and Turkish communities of Antwerp (Belgium). First generation labour migrants settled in the neighbourhood of the mines and in industrial belts, for instance in the provinces of Limburg, Hainaut and Liège, and in large urban areas, such as Brussels, Ghent, Antwerp, and Liège. Antwerp was chosen as the setting for our study due to its important number of Muslim migrants today. Moreover, choosing Antwerp as our research setting allowed us to rely on and to deepen a previous study conducted at the Interdisciplinary Centre for the Study of Religion and World View (KU Leuven) by dr. Stef Van den Branden (2006).

Like dr. Van den Branden we opted to interview *elderly* (age $\geq$ 60) Muslims living in Antwerp, belonging to the group of first generation migrants. This choice was also made because we wanted to compare their attitudes towards treatment decisions at the end of life with those of elderly Jewish women living in Antwerp (see part 1). Unlike Van den Branden we did not restrict our study to Moroccans, Turks were included as well. Given the segregation of the sexes in Islam, as a *female* researcher we only recruited Muslim *women* to participate in the study.

Since the participants did not (sufficiently) master Dutch, and the interviewer did not speak (Moroccan) Arabic and Berber, she was assisted by two experienced female interpreters, one of Moroccan origin, speaking fluently Dutch, (Moroccan) Arabic and Berber, and one of Turkish origin, speaking fluently Dutch and Turkish. The interpreters also functioned as cultural brokers, and helped the interviewer with gaining access to the communities and with recruitment of interviewees. The interviewer had a basic knowledge of Arabic – she completed a four-year course of Arabic at the CLT Language Centre in Leuven – which sometimes helped to break the ice. Despite this and the valuable assistance of the interpreters, especially in the Moroccan community it was difficult to find women who were willing to participate. Several explanations can be offered for this. First, elderly first generation Moroccan and Turkish women live rather isolated from society; they are often illiterate and not able to express themselves in Dutch. Second, a lot of women who were asked to participate proofed to be shy and did not understand why the academic world would be interested in *their* opinion. Regularly, they advised us to contact an expert of Islam. Third, all this is related to strong mechanisms of social control which are felt in Muslim communities. Frequently, contacted women seemed to be afraid to be interviewed, and refused the interview to be audio-taped. Recruitment of participants and interviewing in the Turkish Muslim community of Antwerp ran more smoothly than data gathering in

the Moroccan Muslim community. Similarly, in their study among Turkish and Moroccan populations in Belgium, Lesthaeghe and Neels (2000) found a substantially higher response rate among Turks than among Moroccans ("many Moroccans wanted to be interviewed in locations where they could not be seen" (Lesthaeghe 2000b, p. 26)). They explain this by referring to the internal fragmentation and heterogeneity in the Moroccan communities in Belgium, in contrast to the strong cohesion among Turks.

Data gathering in the Moroccan and Turkish Muslim communities of Antwerp started in June 2009 and ended in January 2011. Recruitment continued until no new elements emerged from further interviewing. At that point, theoretical saturation was reached. Apart from interviewing, the interviewer gave attention to participatory observation (several Friday prayers in mosques, Quran classes, and a commemoration of a deceased person were attended). Despite troubles of recruitment and data gathering, finally 30 Muslim women (15 Moroccans and 15 Turks) consented to take part in the study. Given the fact that we were unable to find enough women over the age of 60, we also included a few women of age $\geq$ 55. Most participants were of very humble descent, uneducated and illiterate. In the table below, we give an overview of the Moroccan and Turkish interviewees. We mention their name (pseudonym), native region, age, migration year to Belgium, number of children (Child.), and their knowledge of languages [(m) stands for mother tongue; (l) stands for (very) little knowledge].

(a) Moroccan interviewees

Name	Native region	Age	Migration to Belgium	Child	Languages
Hakima	Oujda	63	1976	8	Berber (m) Arabic (m) Dutch (l) French (l) Spanish (l)
Mina	Nador	60	1980	5	Berber (m) Arabic (l) Dutch (l)
Rahma	Oujda	61	1972	0	Berber (m) Arabic French Dutch (l)
Jamila	Nador	67	1969	14	Berber (m) Arabic (l)
Fatiha	Tanger	61	1968	7	Arabic (m) Dutch (l)
Hanan	Nador	70	1973	7	Berber (m) Arabic (l)
Mimount	Tanger	61	1964	6	Arabic (m) Berber (l)

					Dutch (l) French Spanish
Zohra	Casablanca	59	1971	8	Arabic (m) Dutch (l) French
Mariam	Nador	62	1968	3	Berber (m) Spanish (l) Dutch (l)
Aziza	Nador	64	1980	5	Berber (m) Arabic Dutch (l)
Habiba	Tanger	55	1974	5	Arabic (m) French Dutch (l)
Yamina	Al-Hoceima	60	1970	10	Berber (m)
Farida	Tanger	73	1965	7	Arabic (m) Dutch (l) Spanish Berber
Malika	Tetouan	71	1964	9	Arabic (m) Dutch (l)
Saida	Taounate	70	1965	0	Arabic (m) French Dutch (l)

(b) Turkish interviewees

Züleyha	Bursa	71	1964	3	Turkish (m)
Esra	Mugla	68	1971	5	Turkish (m)
Lale	Samsun	75	1963	9	Turkish (m)
Pinar	Emirdag	67	1967	4	Turkish (m) French (l) Dutch (l)
Mehtap	Emirdag	61	1975	6	Turkish (m) Dutch (l)
Dilek	Nevsehir	70	1965	7	Turkish (m) Dutch (l)
Hülya	Tokat	56	1969	4	Turkish (m) Dutch (l)
Ayten	Sivas	63	1977	3	Turkish (m) Dutch (l)
Zehra	Emirdag	59	1972	4	Turkish (m)
Kezban	Corum	61	1977	1	Turkish (m) French (l) Dutch (l)
Handan	Sivas	65	1972	4	Turkish (m)
Özlem	Emirdag	56	1971	4	Turkish (m) French (l)

					Dutch (l)
Gamze	Kayseri	65	1966	0	Turkish (m) Dutch (l)
Bahar	Bozkurt	55	1976	7	Turkish (m) Dutch (l)
Ferhunde	Konya	55	1975	4	Turkish (m) Dutch (l)

11 "Be patient and grateful". Elderly Muslim Women's Responses to Illness and Suffering

11.1 Introduction

The provision of spiritual support is rapidly becoming an integral dimension of care for hospitalized, often critically ill, patients. Palliative care models recognize that care at the end of life is multidimensional, strongly incorporating the humane character of healing and care. Palliative care programs are built on several pillars focused on balancing the physical, psychological, social, emotional and spiritual needs of terminally ill patients . Cicely Saunders, founder of the modern hospice movement in South London, England, (1967) developed the concept of "total pain" emphasizing that the experience of suffering is multifaceted (Clark, 1999; Clark, 2000). She recognized that "pain is a deeply personal experience that cannot be understood as merely a biological phenomenon" (Paz & Seymour, 2004, p.279). Pain management in critically ill patients is complex to be approached holistically. Apart from physical care, total care of patient and family facing imminent death includes assessing and addressing the social, psychological and spiritual factors (Ferrell, Levy, & Paice, 2008). Easing pain encompasses more than just providing analgesics.

When confronted with patients experiencing existential and spiritual distress, nurses and physicians routinely refer patients to hospital chaplains. Many terminally ill patients may wrestle with existential questions and experience severe spiritual suffering (Millspaugh, 2005). They may express a desire to talk to a spiritual counsellor when trying to cope with illness and suffering in relation to transcendental realities. Palliative care chaplaincy has routinely been understood and addressed from a Judeo-Christian context (Abu-Ras & Laird, 2011). Given the "transformation of a once-Christian West into a post-Christian or at least a post-traditional Christian culture" (Engelhardt, 2003), "spirituality is [currently recognized as] a fundamental need that goes beyond religious affiliation" (Rassool, 2000). This shift highlights an increasing need for spiritual counsellors from a variety of faith and cultural backgrounds (Schmidt & Egler, 1998). Islam is currently the fastest growing religion in the West. Understandably, Muslims increasingly seek Western health care. The need for more health care routinely rises with increasing age. Today's health care providers are treating Muslims (Talloen, 2007; Lodewijckx, 2010). The ways people view medicine and the ways they understand illness and interpret symptoms may relate to and be influenced by their religious and spiritual beliefs (Coleman, Koffman, & Daniels, 1997; Bradshaw & Fitchett, 2003; Ypinazar & Margolis, 2006; Van den Branden & Broeckaert,

2008; Harandy et al., 2010; Zeilani & Seymour, 2010; Ahmad, Muhammad, & Abdullah, 2011). Muslim patients might have distinctive spiritual needs related to a underlying theological framework quite different from western traditions. Thus, in addition to their physical health care needs, Muslim patients bring their specific cultural, religious and spiritual needs. This reality may challenge care givers including chaplains to "accommodate the vast variety of faith traditions" (Cadge, Calle, & Dillinger, 2011).

Given these important shifts in Western (European) societies this article represents one attempt to highlight Muslim views on illness and suffering. We report on the results obtained from a small study aimed at illuminating the conceptions about health and health care of elderly Muslim women living for nearly fifty years in Antwerp (Belgium). As non-Muslim researchers interested in religious studies, and specifically in the way adherents of different religions deal with illness and suffering, we take a non-normative, descriptive, exploratory approach. This means that we are neither willing nor able to formulate normative standpoints on the issue at hand.

11.2 Method

Given the separation of genders in Muslim cultures and the female interviewer (1st author), purposive sampling for qualitative interviewing was restricted to Muslim women. Thus, the purpose of this small-scale exploratory study was to elicit viewpoints of Muslim women (age ≥55) living in Antwerp who migrated from Morocco or Turkey to Belgium as young ladies between the early 1960s and early 1980s. In-depth, semi-structured interviews were conducted with 15 Moroccan and 15 Turkish women, who consented to cooperate and to have their interviews recorded. Questions were asked regarding their personal context, family situation and migration history, and the interviewer inquired about their religious beliefs, their experiences with growing older, and their attitudes toward health, illness, death, medicine and concrete treatment decisions in advanced disease. All interviews were conducted individually and in a quiet place. The interviewer was assisted by two female interpreters fluent in Arabic/Berber (Tarifit) and Turkish. These interpreters were respectively members of the communities from which participants were drawn. They also functioned as cultural brokers, facilitating recruitment of participants and adherence to cultural sensitivities, helping the non-Muslim interviewer to understand specific cultural habits and religious convictions. Data gathering was completed when no new information was forthcoming from the interviews. At that point, theoretical saturation was reached. Each interview was transcribed verbatim immediately after the interview was concluded. The data were coded inductively using a Grounded Theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1998). The data's key concepts were identified and categories were

generated and interrelated, making use of qualitative data analysis software (MAXQDA 2007). Findings were frequently discussed with the Muslim interpreters and the research supervisors. All quoted interviewees' names have been replaced by pseudonyms in order to guarantee anonymity.

11.3 Results

11.3.1 Sample characteristics

Our interview sample was composed of 30 Muslim women having Moroccan (n=15) and Turkish (n=15) roots, aged between 55 and 73 years. The Moroccan participants were born in northern Morocco; Berber (Tarifit) or Moroccan was their native language. Participants whose mother tongue was Turkish were born in the western, northern or central provinces of Turkey. All of them migrated to Belgium between the early 1960s and early 1980s and were spouses of young male 'guest workers'. By contrast with their husbands, who were employed for many years as miners or steel workers, the majority of the interviewees were housewives. Most of them who settled in the country were illiterate and uneducated. Sixteen interviewees were married, 9 were widows, and 5 were divorced. They each reported to have between 0 and 14 children, born either in their country of origin (Morocco or Turkey) or in Belgium.

11.3.2 Perceptions of medicine, health and illness

11.3.2.1 "For every illness, God created a treatment"

All participants were convinced that God is the creator of illness. Given their faith in God's omnipotence, they reported a belief in a God that is the almighty creator and governor of the world. As such, the interviewees explained, Allah creates life and death, health and illness.

> If you are walking and suddenly you fall, it's because of Allah. Allah gave us life, and if we fall, if we fall ill, then we think it's all because of Allah. (Esra - Turkish)

The participants stressed that illness should not be approached passively; illness should be fought. All interviewees considered it important to seek treatment; they considered doing so as Allah's own commandment. They stressed that God commands to take care for life and body which have been created by God himself. Not caring for one's health and body constitute disrespect to Allah. Thus, despite their faith in God's

omnipotence, the participants stated that consulting a doctor does not contradict Allah's sovereignty and does not give evidence of ingratitude to or mistrust of Allah.

> Allah gives illness but we have to do something against it. If we go to the doctor, we must do everything to be cured. (Rahma - Moroccan)

> Illness comes from Allah, and cure as well. But there are doctors too. Allah has given illness, but there are doctors too. You have to go to the doctors. Maybe there are... Maybe there are a lot of diseases, but there are also a lot of treatments. (Kezban - Turkish)

Most participants expressed trust in medicine and considered doctors to be erudite. Moreover, physicians and medications, themselves, were considered to be God's creations. Accordingly, consulting doctors and taking medication was completely legitimate. However, the interviewees contrasted physicians' knowledge with Allah's omniscience. They shared the opinion that despite doctors' efforts, in the end cure is effected by Allah, meaning that God *can* grant cure by means of physicians and medication. Whether doctors' prescriptions and medication will be effective, depends completely on God's plan. Ultimately, they explained, Allah is the highest doctor.

> Allah says 'you have to consult a doctor, and I will do the rest'. (Mariam - Moroccan)

> Cure comes from Allah. When I'm ill, for instance bronchitis, I must go to the doctor. And I must take my antibiotics and I will be cured. But if Allah does not want it, maybe a more serious illness will happen to me. (Hülya - Turkish)

11.3.2.2 Be grateful to Allah...

In response to illness, the interviewees explained, Muslims not only put trust in science, but first and foremost, they rely on *Allah*. While doctors can only try to help sick people, in contrast to these earthly scientists, *Allah* can determine everything, and if necessary, Allah can even reverse the laws of nature.

> Allah is greater than the doctor. Allah is the greatest. Allah is the professor. For everyone. Allah gives my eyes, Allah gives my ears, Allah gives my tongue, my food. Everything is from Allah. Not from the doctor, from Allah. (Zohra - Moroccan)

The interviewees maintained that human beings' response to illness must be twofold. Apart from seeking remedy, an ill person must turn to God in grateful prayer. Thus, on the one hand, the interviewees expressed the view that illness must be fought. On the other hand, they stressed that patiently enduring illness and suffering is of utmost importance, as it gives evidence of gratitude to God. Complaining about illness is altogether wrong.

> You must accept it. When you say 'Oh, I'm fed up with it', that's not good. Allah gives the pain, money or health, or... But you must accept. You must stay calm. (Mimount - Moroccan)

> We must be patient and say 'alhamdulillah' (praise be to Allah). We must not complain. (Mariam - Moroccan)

> Allah puts us to the test, whether in illness you stay patient and grateful to Allah, and whether you pray to Allah. It's Allah's testing. (Ayten - Turkish)

11.3.2.3 ... in order to pass the exam

The preferable way for coping with illness advocated by the interviewees can be linked to their interpretation of illness and suffering along with their very specific eschatological beliefs. The participants offered different interpretations of illness and suffering. Commonly, they shared the perception that illness is Allah's testing. In the course of the interviews, the participants frequently highlighted the importance of performing good deeds during life. They reported all aspects of life, including illness and suffering, to be part of God's exam that humans can either pass or fail. The interviewees explained that a Muslim's purpose in life is to gather good marks which will enhance one's chances to be rewarded in the afterlife. For those who behaved well, paradise is awaiting; sinners are due for punishment in the hereafter. Given this teleological perspective, the interviewees emphasized that it is of utmost importance to bear patiently God's afflictions including illness and suffering. Sick people who complain will not pass the exam.

> In our faith, when you wait patiently, in the other world, you will experience welfare. *Sabr* (patience) results in *selamet* (well-being). (Özlem - Turkish)

> If you accept your illness, you get another good mark. It's a test. (Mariam - Moroccan)

For the majority of the Turkish and Moroccan interviewees, bad behaviour in life and illness were closely linked. They explained that illness could be the result of wrongdoing. Most participants, however, opposed interpreting illness as punishment. On the contrary, illness was rather perceived as a greeting and blessing from Allah. The interviewees clearly shared the notion that through illness people get the chance to be cleansed from sin.

> Someone who behaved bad, someone who suffers a lot of pain, this means that his sins diminish. If Allah wants him to suffer, this means that he is a bit purified from sin. And if he dies, he will go to paradise. (Fatiha - Moroccan)

> It's written in the *hadith* (words and deeds of prophet Muhammad) that people who are ill for a while pay the penalty, because they have done something wrong. But if they die, they go to paradise, they are purified. (Yamina - Moroccan)

> If you fall ill, your sins, what you have done wrong. If you fall ill, I hope to be purified from sin, *insha'Allah* (if God wills). (...) Illness comes from Allah. You must not be mad at Allah, because Allah has given you illness. You must say, you must not be mad at Allah, you must be grateful. In this way, maybe your sins are purified. (Pinar - Turkish)

These quotes reflect the dominance of a shared teleological perspective: getting the chance to be purified from sins in earthly life opens good perspectives in the hereafter on the condition that afflictions are endured patiently and gratefully. Although emphasizing the importance of patient endurance, a few participants were rather hesitant to provide an explanation for illness. God and illness were closely linked, but they refused to express their view about *Allah*'s intentions with giving diseases and suffering. Seeing that humans are restricted beings totally dependent on God's inscrutable plans, they preferred not to pass judgement on things human beings do not know anything about. For them, giving an explanation for illness would be equal entering *Allah*'s domain illegitimately. Jamila (of Moroccan origin), for instance, had just returned from the *Hajj* (pilgrimage to Mecca) which is perceived as having a purifying effect. She reported fear that judging God's deeds would (result in low marks on her report. Similarly, Malika (of Moroccan origin) expressed the view that only God knows her intentions. Similarly, Lale and Esra (of Turkish origin) preferred not to give an explanation for illness: only *Allah* knows why he burdens people with illness and suffering.

- Everything is from Allah. Being in the womb of your mother for nine months,... Illness too comes from Allah.
- Why would God want to make people ill?- Only Allah knows it. [...] Being healthy, being ill, everything is from Allah. Allah knows it. For instance, I fell off the stairs, it's also because of Allah. (Esra - Turkish)

We cannot intervene between Allah and human beings. We cannot judge about it, because I went to the Hajj, and I don't want to judge. (Jamila - Moroccan)

11.4 Discussion

The participants' comments reflected the literal meaning of Islam: 'submission'. The interviewees' utterances reveal that they commonly aspire to submit to Allah in all aspects of daily life including the arenas of medicine and illness. It became evident that, for these Muslim respondents, the secular and religious/spiritual realm can be in conflict. The meanings attributed to illness and suffering, as well as the way one is assumed to cope with it, are marked by these Muslim women's religion and spirituality. As such, theological arguments were central throughout the interviews, especially also in the participants' conceptions of medicine, illness and suffering.

Our participants' line of reasoning was similar to the line of thought found in non-empirical normative Islamic approaches on medicine, illness and suffering. In the same way as among our interviewees, in international literature on the issue presenting normative Islamic guidance, the discussion is framed theologically. In their analysis of *e-fatwas* (legal opinions issued by a *mufti*, jurist trained in Islamic law, published on the Internet) on coping with suffering and pain treatment, Van den Branden and Broeckaert (2010) indicate that apart from the discussion on the alleviation of pain, a theological line of thought stressing the importance of patiently bearing pain inheres.

Similarly, other international scholarly literature on normative Islamic approaches of medicine, illness, and suffering, shows that theological considerations remain central. Both normative Islamic guidance and our interview responses support the observation that Allah is central for our participants. Allah's omnipotence, omniscience, and perfection are stressed in contradistinction to the human limitedness (Al-Jeilani, 1987). A human being's course of life is limited, and whether he/she will fall ill, will be cured, and when he/she will die, are all things which are determined by Allah (Rispler-Chaim, 1993). Faith in Allah's predestination reinforces Muslims to submit to God's inscrutable decree. The responses during our interviews reaffirm normative Islamic guidance: illness is not perceived as

random but a trial by God, a test from Allah (Al-Jeilani, 1987; Rispler-Chaim, 1993; Rassool, 2000; Ahmed, 2008). Our participants affirmed the perspective that such divine tests required a human response, a responsibility to mitigate what might be divinely given. Sachedina notes that suffering is connected to human misconduct and "the sin of ungrateful disobedience" (2009, p. 87) and that, through experiencing pain, people are provided the opportunity for self-purification. This cleansing effect of suffering is confirmed by other scholars (Rassool, 2000; Rispler-Chaim, 1993; Atighetchi, 2007; Ahmed, 2008). Sachedina further suggests that that suffering is "for the betterment of humanity" (2009, p. 99), and may contribute to both spiritual and moral growth. On a more cautionary note, he suggests that such expiation of sins will becomes possible only when suffering is patiently endured. In her analysis of (Arabic) *fatwas*, Rispler-Chaim found *sabr* (patience, endurance) to be "the only recourse available to endure suffering" (1993, p. 99). Thus, illness and suffering are regarded as God's mercy and blessing through which human beings can earn merits, and not as a curse or an evil (Atighetchi, 2007; Sachedina, 2009). At the same time, Atighetchi adds, "Islam does not exalt suffering" (2007, p. 208). Likewise, the importance of pain treatment was stressed by our respondents, while, at the same time, they tended to regard suffering as meaningful.

Our participants remained consistent with normative Islamic guidance: coping with illness and suffering is framed eschatologically (Rispler-Chaim, 1993). Brockopp emphasizes this teleological perspective in Islam, stating that Islamic theology and law do not focus "on the pain and suffering of this world, but on God's promise of eternal life in paradise" (2003, pp. 189-190). Reliance on Allah means a balancing. On the one hand, obeying God's commandment to seek treatment, and, on the other hand, patiently accepting suffering, will bring prosperity in the hereafter. As such, like our empirical data from a very limited but seemingly coherent cohort indicate, normative Islamic guidance shows that Muslims essentially live with the future perspective of the hereafter, and that, for them, their earthly deeds acquire great significance.

Other studies among Muslims confirm the link between religion, illness and health perceptions (Ypinazar & Margolis, 2006; Van den Branden & Broeckaert, 2008). Ypinazar and Margolis (2006) interviewed older (age ≥65) Arabian Gulf Muslims. Comparable to our study, in their participants' narratives about health and illness, religious beliefs were closely interwoven. Central theological elements which came forward from that study, and which were similar to ours, were: Allah's commandment to seek healing, and health and illness as part of Allah's immutable decree. Very similar data were discovered in the study of Van den Branden and Broeckaert (2008) who interviewed elderly Moroccan Muslim men living since the early 1960's in Belgium (Antwerp). In the same way as the *female* interviewees in our study, the *men* they interviewed continuously lived with the future perspective of

judgement by the almighty God in the afterlife. In this sense, life was perceived as a test, and observation of a good Islamic way of life was thought to be essential given this future perspective. Similar to the comments of our female participants, for these male interviewees, life centred on Allah and submission to Allah's will. Thus, analogous to our study, theological elements were dominant in our interviewees' stories. Although the findings of both studies were nearly identical, one difference was found. One female (Moroccan) Muslim woman in our study deviated from the standard position. Saida did not link illness and suffering to Allah. Interpreting illness and suffering as "evil", she was of the opinion that God only creates good things for human beings. For her, seeing Allah as the creator of illness and suffering was unthinkable. Her deviating answer might be related to her husband's agony near the end of his life, or to her rather isolated position in the Moroccan community. She was childless, had no family in Belgium, had only scarce contacts with other Muslims in Belgium, and never attended mosque prayer. An open questions remains about whether gender differences might play a role. The central significance of Allah in life and upon confrontation with illness, is also confirmed by situational qualitative empirical studies among female Muslims who experienced critical illness and suffering (Harandy et al., 2010; Zeilani & Seymour, 2010; Ahmad, Muhammad, & Abdullah, 2011). Zeilani & Seymour (2010) demonstrate that spirituality helped critically ill Jordanian Muslim women to cope with their suffering. Illness was interpreted to be part of God's will and as a test sent by Allah. Patient endurance of illness was believed to lead to purification of sins. Prayer was described as a means of helping to accept illness and endure suffering. In the same way, Iranian Muslim breast cancer survivors in the study of Harandy et al. (2010) attributed their cancer to Allah's will. Again, spiritual beliefs were of significant help in coping with illness, and had an important comforting character. Similar theological elements came forward: disease as a divine test, Allah as the governor of life and death, submission to Allah's will and acceptance of Allah's plan.

Harandy et al. (2010) stress the notion that the importance of surrendering to God's will did not lead to fatalism. On the contrary, all participants reported to have actively sought for medical treatment. The spiritual and religious approach to illness, without lapsing into fatalism, was confirmed by Ahmad, Muhammad & Abdullah (2011) who interviewed Malaysian Muslim women surviving advanced breast cancer. Again, spiritual resources seemed to offer important support for dealing with critical illness. Coping with illness and suffering had a strong theological slant. The participants believed that illness did not occur coincidentally; they saw it as a gift from Allah. Like among our interviewees, illness was not interpreted as a punishment but as God's blessing, an expression of God's love and mercy. In the same way, they saw it as a test of their gratefulness to Allah to which they should patiently surrender in order to come closer to him.

The reasoning found among people who had been confronted with illness and suffering in other studies was very similar to our findings from interviewees who were *not* critically ill. Most participants claimed that their spirituality and religious beliefs helped them to face illness with a positive approach. The centrality of Allah and the perspective of life in the hereafter "became their greatest motivator to continue surviving and being committed to continuous self-development" (Ahmad, Muhammad, & Abdullah, 2011, p. 43). Our research data, which are consistent with conclusions of other studies, reveal very clearly, first, that Islam is a religious and spiritual entity which carries with it an entire way of life, and second, that spiritual and religious resources can provide an important support for effective coping with illness. This finding reinforces the importance in paying attention to physical comfort treatment along with healthcare spiritual well-being of Muslim patients including those who are terminally ill.

Hospital chaplains, to whom care givers often appeal when they are confronted with patients' spiritual suffering, are integral members of the medical team (Cadge, Calle, & Dillinger, 2011). Being acquainted with patients' coping with theodicy questions and the meanings they attribute to illness may provide insight into patients' very concrete medical choices. Spirituality not only incorporates faith-specific prayers and rituals; it has implications on patients' coping with concrete medical decisions. Muslim patients, for instance, not only need ritual support, for which they can often rely on the community or local imams, they also may benefit from spiritual counselling. In cases in the United States and Western Europe, where hospitals may not be able to rely on trained Muslim chaplains, it is "crucial for Western-trained chaplains to be educated in the practices of Islam as it relates to illness and death" (Abu-Ras & Laird, 2011, p. 48) in order to provide "culturally appropriate spiritual counselling" (Schmidt & Egler, 1998, p. 49). Only in this way, a trust-based relationship can be developed.

Important efforts have been made in the United States to extend spiritual counselling from chaplaincy with a Judeo-Christian connotation to inter-faith or multi-faith chaplaincy, serving outside the particular boundaries of religious affiliation (Abu-Ras & Laird, 2011; Abu-Ras, 2010). Nevertheless, Abu-Ras and Laird (2011) point to the fact that Muslim patients would profit from engaging more Muslim chaplains in hospitals. Their empirical study in New York City hospitals points to the limitations of inter-faith chaplaincy and argues in favour of employing more well-trained Muslim chaplains "who might be able to provide more culturally and spiritually sensitive services to patients" (Abu-Ras & Laird, 2011, p. 57). Of course, in hospitals situated in areas with a large Muslim population in the United States and Western Europe, Muslim patients would profit from engaging Muslim chaplains in hospitals. In case of Muslim patients, and in case health care practitioners are not familiar with Islamic views, Muslim chaplains could point to very

practical consequences of people's spiritual coping with illness and suffering, and to specific sensibilities (Abu-Ras & Laird, 2011). For example, spiritual counsellors could make clear that, in case of caring for Muslim patients, healthcare professionals should be careful with disclosure of information, especially with disclosing a negative diagnosis or with putting forward a life prognosis, and that they should always remain hopeful about a patient's condition, given Muslims' perceptions of doctors' limitedness in contrast to Allah's omniscience. Apart from pointing to specific sensibilities, religious beliefs and customs of Muslim patients, Muslim chaplains could also help to avoid potential pitfalls of stereotypes. On the ward, they can point physicians and nurses unfamiliar with Islam to approach Muslim patients individually, thus acknowledging that Islam is not a monolithic entity. Even in an apparent homogeneous group, like in our study, diversity can be observed. Therefore, Muslim patients should not be reduced to a static Islamic identity. In contrast, pastoral and other caregivers should acknowledge that patients are shaped by various factors, including the religious, but also cultural and biographical milieu in which they live. Thus, in order to provide effective treatment, a full appreciation of patients' religious, ideological and cultural systems in which they live is necessary, as well as attending to their individual issues and needs. As such, it is nonsense to attempt to develop a fixed codex indicating how to treat people from a specific ethnic or religious group. (Talloen, 2007).

Findings of our exploratory study are limited by the small sample size and the assistance of interpreters during the face-to-face interviews. Furthermore, despite important similarities between our non-situational study and other situational qualitative studies on the topic at hand, it would still be interesting to investigate in-depth the impact of personal confrontation of Muslims with terminal illness on the meanings they attribute to illness and suffering. Additionally, large-scale follow-up research could scrutinize possible gender and age differences. As mentioned, our findings show an almost homogeneous viewpoint on medicine and illness This homogeneity can be explained by the fact that we interviewed a very particular subgroup of Muslims: elderly first generation Muslim women (age $\geq$55), having migrated to Antwerp (Belgium) between the 1960's and 1980's, being uneducated and illiterate, and living quite isolated from (Belgian) society. Further studies could explore if the impact of religion and spirituality in coping with illness and suffering would differ among younger generations of Muslims, who tend to live less isolated from Western secular society. Given the nature of our data, which may not be representative of other sub-groups of Muslims, we are prudent in generalizing our findings, and we acknowledge that further in-depth investigations of the matter are necessary.

11.5 Conclusions

The findings of our limited qualitative empirical study suggest that meeting the spiritual needs of patients constitutes an important component of healthcare. Not only chaplains, who act as spiritual counsellors in hospitals, but healthcare professionals as well, should be aware of the impact of religion and spirituality on patients' well-being. As such, it is necessary to take chaplains' contributions to patient considerations on the ward seriously. In particular, the study suggests that Islam offers Muslim patients important resources to cope with difficult periods in life. Theological considerations, centering on God's almightiness, seem to be very central for Muslim patients. Their deep belief in God gives them strength to deal with illness and suffering in a meaningful way.

12 "It's in God's hands". The Attitudes of Elderly Muslim Women in Antwerp (Belgium) toward Active Termination of Life

12.1 Introduction

In contemporary bioethical discussions, dominant Western approaches take the lead. A lot of literature deals with complex bioethical dilemmas from either a secular or a Christian point of view. Nevertheless, over the past few decades, Western societies have undergone considerable transformation. On the one hand, religion has lost influence, resulting in processes of secularization. On the other hand, foreign religions settled in the Western world. As a result of different migration waves to the West, Islam, for instance, has gained considerable ground as religious force, and is the second largest religion in the United States and Europe (Hunter 2002).

During recent years, a number of publications have included discussions of contemporary bioethical problems from a normative Islamic point of view (Atighetchi 2007; Brockopp 2003a; Brockopp & Eich 2008; Rispler-Chaim 1993; Sachedina 2009) and a large number of fatwas (legal opinions) have been issued by Islamic religion scholars through different media. The number of fatwas, which try to provide an answer to a specific bioethical query, that have been published on diverse websites dealing with Islamic good practice is striking (Van den Branden 2006; Van den Branden & Broeckaert 2010; 2011a; 2011b).

Despite this growing attention to a particular Muslim approach for ethical dilemmas in medicine on the part of (Muslim) scholars and physicians, inductive, empirical approaches to the topic are lacking. Obviously, a lot of Western health care professionals today take care of Muslim patients, and the number of publications addressing the need to provide care which is sensitive to their religion and culture is increasing (Gatrad & Sheikh 2002; Gatrad *et al.* 2005; Hedayat & Pirzadeh 2001; Ilkilic 2007; Klein 2000; Lawrence & Rozmus 2001; Padela & del Pozo 2010; Sheikh & Gatrad 2008a; Westra, Willems & Smit 2009). Nonetheless, empirical research that aims to elicit the views of particular groups of Muslims living in the Western world on specific ethical dilemmas in health care is scarce (Van den Branden 2006; Van den Branden & Broeckaert 2008). Therefore, this article deals with the attitudes of elderly (Turkish and Moroccan) Muslim women in Antwerp (Belgium) – all potential patients in a Western health care system – toward active termination of life.

In 2002 Belgium has approved a voluntary euthanasia act, that did not penalize a physician who deliberately ended the life of an incurable adult (≥18 years) patient, suffering unbearable and untreatable pain, at this patient's conscious, voluntary, well-considered and

repeated request (Belgisch Staatsblad 2002). This provoked considerable debate on the right-to-die discourse underlying the act among predominantly non-religious humanist and Christian thinkers. A large part of the Belgian population is in favour of euthanasia and can be expected to support the euthanasia law, consistent with a secular emphasis on a person's right to self-determination, including in the realm of death (Cohen *et al.* 2006a; 2006b; Draulans & Billiet 2011; Elchardus, Chaumont & Lauwers 2000; Smets 2011). Part of the explanation for this is the declining influence of the Catholic Church in Belgian society. Nonetheless, while the Belgian citizen's self-identification with Catholicism and Christianity decreased, migrants imported their own, predominantly Islamic, faith. As a Semitic religion, emphasizing faith in a transcendent God, who is considered to be the creator of life and death and the determiner of a person's life span (Sedgwick 2006), Islam conflicts with a secular right-to-die discourse (Atighetchi 2007; Rispler-Chaim 1993).

Muslim migration to Belgium started off in the early sixties of the twentieth century. At that time guest workers from Muslim countries, predominantly from Turkey and Morocco, were recruited in large numbers to perform cheap labour in the Belgian (mining) industry. Ever since, the Muslim population in Belgium has increased significantly, partly also as a result of the family reunification policy (Lesthaeghe 2000a; Reniers 2000; Surkyn & Reniers 1997). Today, approximately 600.000 Muslims live in Belgium. First generation Moroccan and Turkish labour migrants – having migrated to Belgium between the early sixties and early eighties – mainly settled in mining and industrial areas (e.g., in Limburg and the French speaking part of Belgium) and large urban agglomerations (e.g., Brussels and Antwerp). Although many of these young adults originally had the intention to return to their home country, most of them never did after earning money from their newfound employment.

Today, Belgian society – like other Western European countries – is confronted with a greying Muslim population (White 2006) which likely will not be spared from the infirmities of old age. In Flanders, about ten percent of the older foreign population (age 55+) comes from North-Africa (predominantly Morocco), and about ten percent come from Turkey. Particularly in the city of Antwerp, a significant number of people over the age of 55 – almost ten percent – are of foreign origin, primarily South-European, North-African, or Turkish. In 2004, 8000 elderly persons (age 55+) of North-African and 6000 of Turkish origin lived in Flanders; in Antwerp there were about 3000 elderly North-Africans and 1000 elderly Turks (Lodewijckx 2010). Due to family reunification policies and the prevailing wish of elderly Muslim people residing in Belgium not to return to their home country, this society will face a sharp rise in the ageing Muslim population. The frequent use of health care, particularly among older populations, is accompanied by a need to address ethical dilemmas about important decisions concerning illness and health. As such,

in view of the increasing number of (ageing) Muslims relying on Western health care, we consider it very meaningful to determine what elderly first generation Muslim migrants, having lived in Belgium for nearly fifty years, think about actual ethical issues in health care. The objective of this study was to determine how they deal with the popular Western right-to-die discourse and present-day debates on a patient's active termination of life.

12.2 METHODS

From June 2009 until January 2011 in-depth interviews were conducted in the Moroccan and Turkish communities of Antwerp, Belgium. Given the female sex of the researcher and the common separation between men and women in Muslim communities, we opted to do snowball sampling among elderly first generation Muslim *women* having Moroccan and Turkish roots.

The participants were asked to provide the interviewer (1st author) with more demographic information about themselves (e.g., their migration history and family situation), and the interviewer inquired after their religious beliefs and their attitudes toward treatment decisions at the end of life. The participants were interviewed separately, in a quiet place (e.g., in their own house or a room made available by a local non-profit organization), with the help of two (female) interpreters fluent in Arabic/Berber (Tarifit) and Turkish. Aware that interpreters are not neutral transmitters of a message, we acknowledged a possible impact of their own perspectives on the fieldwork. Therefore, after each interview the interviewer and the interpreter discussed the interview data and their personal views on it. All interviewees consented to have the interview recorded.

Interviewing continued until the moment no new information was elicited. At that point theoretical saturation was reached. Grounded Theory methodology (Glaser & Strauss 1967; Strauss & Corbin 1998) was used to analyze the interview data. Immediately after concluding an interview, it was transcribed verbatim. Next, codes were added to the data: key concepts were identified and categories were generated and connected, with the help of qualitative data analysis software (MAXQDA 2007). Findings were regularly discussed with the interpreters and the research supervisors.

In order to elicit the interviewees' attitudes toward active termination of life, they were asked to react to hypothetical cases. The cases were generated on the basis of Broeckaert's typology of treatment decisions at the end of life (2006; 2008; 2009a; 2009b), which was developed in order to provide conceptual clarity regarding ethical dilemmas in health care, such as euthanasia. In his typology, Broeckaert distinguishes between three kinds of active termination of life: (1) voluntary euthanasia, which he defines as "the intentional administration of lethal drugs in order to painlessly terminate the life of a

patient suffering from an incurable condition deemed unbearable, at this patient's request"; (2) assisted suicide, which is "intentionally assisting a person, at this person's request, to terminate his or her life"; and (3) non-voluntary euthanasia, which is defined as "the intentional administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable, not at this patient's request" (Broeckaert 2009a, 111). The clear definitions Broeckaert provides for each of these potential decisions formed the basis for the formulation of the hypothetical cases, which were presented to the interviewees (see Figure 1). The results presented below are illustrated by excerpts from the interviews; most often the quotes reflect the interpreter's translation of the interviewees' responses. The interviewees' names mentioned are pseudonyms.

Figure 1

Case 1: Voluntary euthanasia

A terminal patient, having only a few more weeks to live, is in severe physical pain. The treating physician has been unable to adequately relieve his/her pain. That patient requests his/her life to be ended. Should the physician be allowed to administer a lethal injection?

Case 2: Assisted suicide

A terminal patient, having only a few more weeks to live, is in severe physical pain. The treating physician has been unable to adequately relieve his/her pain. That patient requests medication to end his/her life. Should the physician be allowed to provide drugs so that the patient can end his/her life?

Case 3: Non-voluntary euthanasia

For several months a patient has been in an irreversible coma, breathing spontaneously (artificial nutrition and hydration are administered). Should the physician be allowed to administer a lethal injection to end the life of the patient?

12.3 RESULTS

12.3.1 Interviewees' demographic information

Thirty women (15 Moroccans and 15 Turks) agreed to participate in the study. The participants were between 55 and 73 years of age. The Turkish interviewees were born in the western, northern, or central provinces of Turkey, and spoke Turkish as their native language. The Moroccan participants migrated from northern Morocco. Among them, eight women spoke Tarifit, a Berber language, as their mother tongue, and seven women spoke Arabic. The participants had no or a very limited knowledge of Dutch. All women were first generation migrants, having migrated from their home country to Belgium between the early sixties and early eighties of the twentieth century, joining their husbands who were employed as guest workers in the Belgian (mining) industry. Upon arrival in Belgium, most of these women lived a rather isolated life, as most of them were uneducated and illiterate, doing the housekeeping and taking care of their children. The participants reported having between 0-14 children. Sixteen interviewees were married, nine were widows, and five were divorced. The overwhelming majority of the women had lived in the city of Antwerp ever since their arrival in Belgium.

12.3.2 Is active termination of life acceptable?

12.3.2.1 Case 1: voluntary euthanasia

In order to elicit the interviewees' attitudes toward voluntary euthanasia, a hypothetical case (see Figure 1) was presented to them. All participants, except for Saida (of Moroccan origin) and Ayten (of Turkish origin), unanimously expressed their disapproval of the termination of life in Case 1. In their opinion, requesting or performing euthanasia is irreconcilable with adhering to the Islamic faith. They considered the act to not be acceptable but rather forbidden for Muslims, and to constitute a grave sin.

> According to our faith, it's forbidden. (Özlem - Turkish)

> That's a sin. Only God knows how long the patient will live. A Muslim doctor will never do such a thing. (Ferhunde - Turkish)

Indeed, a considerable amount of the participants equated voluntary euthanasia with suicide, seeing it as a thoroughly sinful act. Others referred to the immoral behaviour of a physician who would be prepared to give a patient a lethal injection. For the interviewees, this physician would clearly be a murderer.

> In our faith it's forbidden, because it is comparable to killing yourself, in fact. And, in our faith it's unacceptable. (Hakima - Moroccan)

> It is not allowed, a doctor should not give that, because she is not allowed to kill herself. In our faith, it's forbidden, in Islam it is unacceptable that you kill yourself. (Mina - Moroccan)

> Then the doctor is, the doctor is a murderer, the doctor will not do that. And in Turkey for sure, doctors will not do that. That's a crime. (Mehtap - Turkish)

> If the doctor does this, he commits a sin. Because that's killing someone. (Zehra - Turkish)

The interviewees equated expressing the wish to die and committing suicide or murder with turning away from God. In their opinion, a patient who asks for euthanasia is an unbeliever, a heretic who will miss out on his/her reward in the hereafter. Indeed, the participants compared life to an exam. During life, God asks human beings to perform good deeds, to obey his commandments and to patiently bear afflictions. In this way humans can score good marks, which will be counted up after death. Depending on this last judgement, one will end up either in paradise or in hell.

> These are people who do not have faith in God, who do not know God. (Bahar - Turkish)

> A person who does not know Allah, does everything. He kills, he murders people, he commits suicide. He can do everything. In our faith, we are not allowed to kill someone and we are not allowed to commit suicide. (Mariam - Moroccan)

> He is a heretic, he does not have faith in Allah. (Malika - Moroccan)

> Someone who commits suicide, will not go to paradise. He does not earn *hassanat* (good marks). (Mina - Moroccan)

The interviewees argued that the patient's illness and suffering are God-given, and thus have to be endured. Opting for death because of unbearable suffering will only bring earthly relief, since after death, as Zohra explained, this person will suffer severely: he/she will burn in hell as he/she failed the God-created earthly test. The interviewees saw patience and endurance as essential virtues to be cultivated by Muslims during life. Opting for one's life to be ended was for them a sign of impatience and ingratitude toward God,

who tests human beings during their life. The participants reported that while pious Muslims accept God's afflictions gratefully, putting their trust in God, persons who proclaim the autonomous right to die do not provide evidence of humility; they distrust God's intentions with humanity.

> That's God's test. He will not pass the test. [...] You have to endure it. This world is a test and you have to pass it. (Kezban - Turkish)

> He does not have faith. He does not have patience, he does not have faith (Hakima - Moroccan)

For the participants, voluntary euthanasia is ethically objectionable given the fact that, for them, God is the only author of life and death. According to the interviewees, human beings are not allowed to take any action to end life; only God decides about a human being's moment of death.

> Life is created by God and it will be ended by God. (Gamze - Turkish)

The reactions of Saida (of Moroccan origin) and Ayten (of Turkish origin) stood in sharp contrast with the answers of the other interviewees, most of them being rather scandalized about the case presented to them. Saida stressed the patient's right of self-determination in Case 1. For her, a patient has the right to choose that his/her life be ended in the case of unbearable pain. Ayten reported that voluntary euthanasia is justified in the case of a terminally ill patient, although, as she mentioned, it is ruled out by Islam.

> If someone asks this, then he is entitled to it. If they ask it themselves. (Saida - Moroccan)

> For me, it's really a very good thing. I heard of it two years ago, and I asked my son. I'm in favour of euthanasia. [...] It's good, it's good. There are not a lot of chances. If there are chances to be cured, OK, but there are no chances. (Ayten - Turkish)

12.3.2.2 Case 2: assisted suicide

According to most interviewees' reactions to Case 2 (see Figure 1), taking medication to end one's life is unacceptable. Several arguments were offered. First, the participants considered it ethically equal to suicide and murder, which are both deemed unforgivable sins, and therefore irreconcilable with living a (pious) Islamic life.

> That's suicide. In our faith, in Islam, this is unacceptable, and if it happens, that person is very weak. (Hakima - Moroccan)

Hakima and other participants expressed the view that not being able to endure illness and pain and choosing to end one's life are signs of weakness, unbelief and distrust of God. A second argument, related to the former, offered by the interviewees was that God is the ultimate author of life and death. They were convinced of the fact that a human being's time of death is predetermined by God. In this sense, they considered ending one's life prematurely as a sign of impatience and even heresy. Indeed, throughout the interviews it was argued that a person who commits suicide turns away from God and from the Muslim community.

> God will take away our life. So, it's not allowed. That's suicide. (Bahar - Turkish)

> He is not a Muslim, but a heretic. They have no patience. They must have patience and wait until death comes. (Malika - Moroccan)

Mariam (of Moroccan origin) and Pinar (of Turkish origin) made mention of eschatological implications of committing suicide. They argued that the earthly world is only a temporary residence, which is of much less importance than the eternal life in the hereafter. Nevertheless, they stressed that the deeds a person performs in this world have serious consequences for his/her life in the world to come. They argued that ending one's own life is a grave sin – the person had no patience to bear God's afflictions and to wait for God's plan to unfold – for which one will be severely punished after death.

> He will go to the fire, because he committed suicide. Allah didn't, he didn't wait for Allah until he would die, he killed himself. Then he will go to the fire. Because he didn't have the patience to wait for his death. (Mariam - Moroccan)

Remaining patient and enduring suffering is the only option when coping with untreatable pain according to the participants. The participants stated that in this way the patient shows his/her trust in God and his/her resignation to God's will. They argued that exercising patience and showing acceptance will be rewarded in the end.

Given Saida's and Ayten's endorsement of voluntary euthanasia, their approval of assisted suicide would not be surprising. Again, Ayten affirmed that a patient has the right to take the decision to end his/her life. Saida, on the other hand, hesitated: she wondered whether a patient who is able to swallow drugs him/herself is ill enough for ending his/her life to be justified. Thus, according to her, ending a patient's life is only acceptable in case

the patient is bedridden, gravely ill, and incapable of autonomously ingesting medication orally. Among the Turkish participants, a few expressed their understanding for persons who would want assisted suicide. At the same time they admitted these persons would fall into sin.

> If a person chooses for this… Everyone has another opinion about it. I can only give my view, my opinion. […] If that person wants it… (Hülya - Turkish)

> It's possible, if he has a lot of pain. […] But it is a sin. […] God has given life and he will take it. […] I understand that patients ask this. […] It's because of the pain. It's not easy for the patient, to suffer so much pain. (Dilek - Turkish)

Farida (of Moroccan origin) preferred not to give her view on the case, stating that "only Allah knows it": only God has the authority to judge the moral quality of a human being's actions.

12.3.2.3 Case 3: non-voluntary euthanasia

After having heard Case 3 (see Figure 1), the Moroccan interviewees unanimously declared that giving an unconscious patient a lethal injection constitutes murder. All Turkish participants, except for Ayten, also agreed with this. The participants argued that these kinds of acts exceed normal, acceptable medicine. According to them, a physician's task is to treat human beings, not to shorten their lives.

> No, it's not allowed. Only God takes away life, not human beings. Doctors exist to help out, to survive as long as possible. (Habiba - Moroccan)

> Then he kills him. A doctor is not allowed to do this. He's not allowed to kill him. The doctor has to treat, not to murder. (Malika - Moroccan)

Again the participants reported that a person's time of death is in God's hands. They stated that human beings are limited, in contrast to God's omnipotence. Therefore, only God knows about the destiny of human beings, and what's more is that everything will happen according to God's predetermined plan. "It's in God's hands", Farida said.

Thus, administering a lethal injection to a patient and in this way effectuating his/her death, was considered to be outright contradictory with leading an Islamic life. Again, the participants mentioned patience and trust as essential characteristics of being a

pious Muslim. Excercising power over human life shows disrespect for God's plan. The interviewees explained that God knows why a person is comatose, and what will be his/her outcome (recovery or death). They stated that since God's paths are hidden and incomprehensible for human beings, one should not give up hope. Excercising power over human life is a grave sin – as it shows impatience and distrust of God – and will result in punishment.

> God may wake him and then he may recover. He has to stay in the coma. (Yamina - Moroccan)

> God knows what his destiny is. And we have to wait. Each human being has a destiny, we Muslims believe that it is written at our birth. He has to stay like this. God knows when it is time, when life will end. (Handan - Turkish)

Hakima and Mina (both of Moroccan origin) stressed that there probably is a good reason why the person in the case is comatose: the coma – being part of God's will – offers him/her the opportunity to expiate his/her sins.

> In Islam, we think he has sinned in his life. And this is a way to atone for his sins and to purify. Yes, it is a kind of purification. If he dies, he will go to paradise. If he accepts that, then it is like his shirt is washed and purified. (Hakima - Moroccan)

Again, Ayten took an exceptional position. Although acknowledging the Muslim faith that only God is the creator of life and death, she argued that she would not want to be kept in an irreversible coma, because of the burdens it would impose on her family.

> I once said to my son 'if I should be in a coma, which is irreversible, you should allow the doctor to give me an injection, I would not want to continue to live like that, in this case I should die'. This I asked my son. I would not want to live like that. [...] But on the other hand I think God will, God knows when it's the time to die. God gave life and God will take it away. (Ayten - Turkish)

12.4 Discussion

The declining influence of religion, specifically of Christianity and Catholicism, in Western societies, indubitably impacts the way ethical dilemmas are approached. In Belgian

society, a shifting of norms and values was felt as early as the 1990s. Data from the European Values Study (Cohen *et al.* 2006a, 2006b; Draulans & Billiet 2011; Elchardus, Chaumont & Lauwers 2000) show an increased permissiveness toward the right of physical self-determination. For instance, in Belgium, the number of people denouncing euthanasia decreased a considerable extent between 1981 (57,7%) and 1999 (22,4%). Today, one out of two Belgians considers euthanasia acceptable (Draulans & Billiet 2011). In their survey among Flemish secondary school students (aged 12-17), Pousset *et al.* (2009) observed that 61% of the participants found euthanasia acceptable in the case of a terminally ill minor (<18 years). A relatively high acceptability of (the legalisation of) euthanasia and/or physician-assisted suicide among the general public in several Western European countries, Canada and the United States was uncovered in a number of studies (e.g. Bachman *et al.* 1996; Clemens *et al.* 2008; Cohen *et al.* 2006a; 2006b; Emanuel *et al.* 1996; Helou *et al.* 2000; Hurst & Mauron 2003; O'Neill *et al.* 2003; Rietjens *et al.* 2005; 2006; Singer *et al.* 1995; Teisseyre, Mullet & Sorum 2005). Smets *et al.* (2011) found a very high acceptability rate (90%) among Belgian physicians. Cohen *et al.* (2006a) linked this increasing euthanasia acceptance among the general Western European public to "a growing support for personal autonomy regarding medical end-of-life decisions". Similarly, Rietjens *et al.* (2006) related the high acceptability of euthanasia among the Dutch general public to the concern to have control over the dying trajectory. The researchers found that acceptance of euthanasia was related to the wish to decide about medical treatments at the end of life and about the moment of death. Another important element was the wish to die with dignity. Rietjens *et al.* (2006) showed that their findings fit in with a dominant mentality in Western societies, which highly values individualism, independence, control, and self-determination.

These results contrast sharply with the findings of our qualitative empirical study, which focussed on eliciting the attitudes of a very particular group of Muslims, namely elderly Muslim women (age $\geq$ 55), who had lived in Antwerp, Belgium, since the 1960's-1980's, were uneducated and illiterate, had not mastered Dutch, and had lived in isolation from mainstream Belgian society. Not only were they predominantly unfavourably disposed toward active termination of life, but also the majority of the participants did *not* make mention of right to self-determination arguments. On the contrary, apart from Saida (of Moroccan origin) and Ayten (of Turkish origin), every interviewee reported that human beings are *not* in control at the end of life. Having unconditional faith in an almighty God, the overwhelming majority of the participants stated that only God has the power to decide when life comes to an end. Additionally, they strongly denounced human beings' autonomy in matters of life and death, considering it as a sign of heresy and impatience. In contrast to surveys of Western public attitudes to euthanasia and physician-assisted suicide, which found an emphasis on a person's absolute right of control at the moment of death, our findings show a strong disapproval of considering a person's moment and way of death as

a human choice. The participants argued that the only appropriate way of dealing with (terminal) illness and unbearable suffering is to adopt a patient, enduring attitude, leaving decisions about life and death in God's hands.

Our study shows a considerable impact of religious convictions on ethical attitudes. Several other studies confirm this link (e.g. Broeckaert *et al.* 2009a; 2009b; Cohen *et al.* 2006b; 2008; Gielen, Van den Branden & Broeckaert 2009a; Inghelbrecht *et al.* 2009; Miccinesi *et al.* 2005; Rurup *et al.* 2006; Smets *et al.* 2011). In their study of the acceptability of euthanasia in Europe, Cohen *et al.* (2006b) showed that acceptance of euthanasia considerably decreased as the level of religiosity increased. They concluded that people who "belong to a religious group, attend places of worship more often and tend to believe in God, life after death, heaven, hell, and sin [...] also tend to consider euthanasia as immoral" (Cohen *et al.* 2006b, p. 753). Our study shows that the image a person has of God has an even stronger effect on the (dis)approval of active termination of life. The overwhelming majority of the Moroccan and Turkish participants were of the opinion that God is the creator of everything, including illness and death. According to them, life unfolds according to God's predetermined plan: whether a person will become ill during his/her life, whether he/she will recover from it, and when he/she will die, are in the hands of God. The interviewees took a future perspective of the hereafter: scoring good marks in this life – by accepting God's plan – was considered to be essential to have a place in paradise. Thus, in the end, God would judge the earthly deeds of human beings.

Our results suggest that people who perceive God as an almighty, all-knowing, judging God, are more likely to disapprove of active termination of life (voluntary euthanasia, assisted suicide and non-voluntary euthanasia), as in this case a person would illegitimately enter God's sovereign domain. In the same way, we found a link between the image Saida had of God and her *approval* of voluntary euthanasia. For her, God is not the cause of suffering and illness. She reported God to be the protector of human beings, and she could not imagine that God wants human beings to suffer. Thus, she conceived illness as a profane fact and stressed the autonomy of human beings in determining how to deal with it. Moreover, Saida's exceptional position might have to do with the loss of her husband, who suffered unbearably in his last moments of life. Similarly, Ayten's view – stressing a human being's right to self-determination with regard to life and death – might be understandable in light of her personal experience; her husband had died a few years ago, suffering from cancer. Thus, personal experiences might have an influence on the way one deals with ethical dilemmas in health care. In the study by Van den Branden and Broeckaert (2008) among elderly Moroccan men in Antwerp, Belgium, on the same topic, one respondent, whose wife was seriously ill, was not able to give his opinion about the acceptability of euthanasia. Hence, similarly, Van den Branden and Broeckaert (2008)

hypothesised that "Muslims who are confronted with actual palliative situations might not have a clear answer" and do not refer to what they believe to be the normative Islamic view. However, at the same time, we observed that Zohra, whose husband and sister died from cancer, vehemently opposed active termination of life, expressing several Islamic viewpoints, which she perceived to be normative. In contrast to the other interviewees who experienced the loss of their husband, Zohra only mentioned this briefly during the interview, while Saida and Ayten dealt with it at great length. The hypothesis that personal confrontation with pain and suffering of patients might result in a (more) positive attitude toward euthanasia, was put forward in other studies. Smets *et al.* (2011), for instance, found that physicians with more experience in treatment of dying persons, were more likely to accept euthanasia for terminal patients

Like our study, other (qualitative) empirical studies did find evidence of a tolerant attitude among some Muslims towards euthanasia. Stress on patients' dignity and their right to self-determination was found among Sudanese medical students (23,4%) who supported voluntary euthanasia (Ahmed & Kheir 2006). Moreover, this study showed that students who had seen more terminally ill patients in the last six months, were more likely to support euthanasia. Cavlak *et al.* (2007) found openness for euthanasia among physiotherapists (48,9%) and physiotherapy students (38,3%) in Turkey. Similarly, Gard *et al.* (2005) found that 31% of the Turkish physiotherapy students they questioned, accepted euthanasia.

Hence, these quantitative empirical studies and our qualitative empirical research confirm that there are Muslims who show openness for euthanasia. Yet, other empirical studies endorse our finding that approval of active termination of life among Muslims is rather exceptional. Among their participants, Qidwai *et al.* (2001) found 9% to be advocates of physician-assisted suicide. Ahmed *et al.* (2001) showed in their study that 15% of the surveyed Sudanese doctors considered euthanasia acceptable in particular circumstances, yet they would not be willing to perform euthanasia themselves. Among his male Moroccan interviewees, Van den Branden (2006; Van den Branden & Broeckaert 2008) encountered a (nearly) general disapproval of active termination of life.

The impact of religious convictions, and more particularly the image of God, on attitudes to active termination of life, is supported by our previous qualitative empirical study among elderly Jewish women in Antwerp, Belgium (Baeke, Wils & Broeckaert 2011b), which found an absolute rejection of active termination of life among the overwhelming majority of Orthodox Jewish women, who expressed faith in God's sovereignty in the domain of life and death. Similarly, these participants believed that God delineates a meaningful plan for every human being, which he/she must accept. Like most Muslim participants they thought God creates health as well as illness, and both were

considered to contribute to the well-being of human beings. Moreover, in the same way as the Muslim participants stressed, the Jewish interviewees mentioned that the way in which human beings cope with afflictions during life, will have consequences in the hereafter, since ultimately, they said, God will judge human beings by their actions. Very similar to our study among the Muslim population in Antwerp, there were those in the Orthodox Jewish sample who did take the exceptional position – approving of voluntary euthanasia. Esther was an Orthodox Jewish woman who stressed a patient's right to make choices with regard to death. Her exceptional position could be linked to her specific theological view, rejecting faith in God's omnipotence and stressing God's restrictedness (Baeke, Wils & Broeckaert 2011b). Like in the case of Saida and Ayten, her personal experiences – she was a breast cancer survivor – might have played a role in her approval of voluntary euthanasia and assisted suicide.

The results of our study among the female Muslim interviewees are in keeping with the findings of Van den Branden (2006; Van den Branden & Broeckaert 2008), who conducted a qualitative empirical research among elderly Moroccan Muslim men living in Antwerp, Belgium, who were first generation migrants (having migrated to Belgium as guest workers during the 1960's and 1970's). Researching their attitudes toward active termination of life (voluntary euthanasia, assisted suicide and non-voluntary euthanasia), the researchers drew conclusions very similar to ours. The male interviewees' rejection of active termination of life was understandable in light of the characteristics they attributed to God. Identical to our female interviewees, they saw God as the sole determiner of the life span of human beings. In the same way, they rejected euthanasia because they saw it as "an autonomous decision made by an individual that is unacceptable precisely because it denies God's role in matters of life and death" (Van den Branden & Broeckaert 2008). Like most of our female Moroccan and Turkish interviewees did, the male Moroccan participants in the study of Van den Branden and Broeckaert (2008) stressed relying on God as the only acceptable way of coping with terminal illness and untreatable pain. Deciding to end one's life would be playing God and would be negatively judged by God in the afterlife. Similar to our research, the idea that life is a test from God and that illness and pain are afflictions of God, which afflict human beings with a good reason (as a test of faith or as redemption of sins), emerged in the interviews.

Although the results of both studies were nearly identical, one difference was discovered. While our study among elderly Moroccan and Turkish Muslim women found a few exceptional pro-euthanasia positions, these were absent in the study of Van den Branden among elderly Moroccan men. Apart from one participant, Driss, who was not able to give his opinion on euthanasia due to personal circumstances (his wife was gravely ill), not a single one of the male interviewees deviated from the standard Islamic position

which condemns active termination of life. Whether these divergent data can be ascribed to gender differences, or whether this is mere coincidence cannot be concluded at present.

Strikingly, in the reaction of our participants to the presented hypothetical cases on active termination of life, a number of theological arguments were cited. This theological line of reasoning is also characteristic for non-empirical, normative Islamic approaches of active termination of life, and for fatwas, responses issued by a *mufti* (jurist trained in Islamic law) directed to a private inquirer (*mustafti*) (Tyan 1965), on a particular bioethical query. International scholarly literature on Islamic medical ethics confirms that active termination of life is often discussed in a theological framework (see e.g., Rispler-Chaim 1993; Atigetchi 2007; Brockopp 2003b; Sachedina 2009; Van den Branden & Broeckaert 2011).

Moreover, in this normative literature a univocal negative answer to active termination of life is found, which is very similar to the dominant approach identified among the interviewees in our study. On the basis of a review of Arabic sources, o.a.. fatwas, Rispler-Chaim (1993) showed that theological considerations rule out ethical debates on euthanasia in Islam. Similarly, Brockopp (2003b) and Atighetchi (2007) show that contemporary Islamic discussions reject euthanasia, seeing it as a reflection of an atheistic way of thinking. Like Rispler-Chaim, Atighetchi makes clear that in Islam active termination of life is prohibited, without exception, on the basis of important religious convictions, coming from the Koran and *Sunna* (sayings and actions of Prophet Mohammed). Brockopp explains that, though *muftis* are concerned about situational elements in making ethical decisions in health care, these decisions inevitably rest within a larger theological and legal framework, "which explains the continued reference to classical texts of theology and law when dealing with very modern issues such as euthanasia" (2003b, p. 177). Specifically, Brockopp (2003b) puts the Islamic euthanasia debate in a teleological framework, stressing Muslims' belief in the soul's destiny (heaven or hell) after the death of the body. He shows that modern fatwas prohibit euthanasia, equating it with suicide, and aim to prevent Muslims from eternal punishment in the hereafter. In the same way, Sachedina shows that in Islam the right-to-die question "cannot be negotiated" (2009, p. 169), given central theological viewpoints. He shows that an Islamic way of life centres around God and his unalterable decree. Being the owner of human life, the creator of everything, including illness and suffering, and the determiner of a person's life span, life and death ultimately are in God's hands, which rules out the possibility of being assisted in dying. Referring to the central importance of a teleological framework in Islam, Sachedina (2009) stresses that in Islam active termination of life is considered to be an act of disobedience against God, for which the patient and the physician will be held accountable.

Similarly, in their study, Van den Branden and Broeckaert (2011) discovered a strong dismissive attitude toward active termination of life in contemporary e-fatwas (legal opinions published on the Internet) dealing with the subject, frequently referring to normative Islamic principles, and equating active termination of life with suicide (from the side of the patient) and murder (from the side of the physician). This results in a very rigid debate on the matter; active termination of life is considered a religious taboo, which should not be discussed. In the same way as other scholars, they make mention of a teleological focus: in the e-fatwas discussing active termination of life, the idea comes forward that "the moment of personal death derives its meaning from the larger scheme of what the soul is awaiting in the hereafter" (Van den Branden and Broeckaert 2011, p. 38). In this sense, the solution which the analyzed e-fatwas propose to suffering – namely, patient acceptance – is understandable.

The dominant reaction of the participants in our empirical study to the hypothetical cases on active termination of life, was strikingly similar to the line of reasoning found in normative Islamic guidance. First, we elicited a strongly denouncing attitude to the matter, treating it as a taboo subject. Both our findings and the normative literature equate active termination of life with murder and suicide, considering these as terrible sins. Second, among the participants of our study, this dismissive attitude was founded on theological arguments. This is also the case in normative Islamic sources on the topic. In our interviews as well as in normative Islamic guidance on active termination of life, every aspect of life seems to be centred around God, who is believed to have omnipotence. Moreover, the literature and our findings show a very similar theological line of reasoning: God is considered to be the master of everything. Consequently, a person does not own his/her body – it is given on loan from God until death – and one has no right to decide to end life. God decides on the life span of human beings, which is believed to be stipulated in God's unalterable divine decree. Seeing life in a larger eschatological framework, the future perspective of (judgment in) the hereafter qualifies a person's actions in this world. In this sense, life is perceived as an exam, and in the same way, suffering is seen as a test and/or an expiation of sins. *Sabr* (patience, endurance) comes forward as the only solution to suffering. Patiently accepting and enduring illness and suffering – ascribing it a purifying effect – is a sign of resignation to God's will and proves one to be a believer who will earn credit with God.

In his analysis of divergent theological responses to suffering in Islam, Sachedina (2009) points to the real danger of a fatalistic attitude which can be adopted in the face of illness and suffering, and which may be erroneously deduced from our interview data. In order to avoid oversimplification with regard to Islamic dealing with illness and suffering, Sachedina (2009) sketches the complex discussion among Islamic scholars throughout

history about the theodicy question. As there is no official Islamic doctrine about (divine) predetermination and (human's) free will, diverse opinions are distinguishable between and within different schools of thought. To be clear, this diversity appeared in our data as well. Elements from determinist theodicy – stressing the absolute will and power of God – were supplemented with elements from free-will theodicy, which point to human responsibility in evil and hence counter a passive and fatalistic approach to illness. Indeed, our interviewees stressed patient acceptance and endurance of illness and suffering – which may at first glance suggest a fatalistic attitude – but at the same time they adopted a positive attitude to medical treatment.

From international literature on normative Islamic viewpoints on active termination of life, it appears that theological considerations, being essential components of the Muslim faith, "have a real effect on the form and content of ethical debates among Muslims today" (Brockopp 2003a, p. 176). The impact of Islamic religious convictions, centring around God's characteristics, on ethical attitudes to concrete hot topics in contemporary bioethical discussions, is confirmed by our empirical study: for the overwhelming majority of the participants, God's absolute omnipotence radically rules out a person's active termination of life. On the other hand, there are exceptions; within Saida's image of God, who is not an *almighty* protector, euthanasia is acceptable.

Hence, our findings revealed a significant impact of a theological frame of reference when dealing with concrete bioethical dilemmas, which shows that for our participants being Muslim affects all everyday aspects of life. The theological frameworks uncovered in our specific respondent group differ substantially from liberal right-to-die discourses which are quite popular in Western Europe and are strikingly similar to theological arguments present in normative Islamic discourses.

At the same time, we acknowledge that the Islam-*versus*-West analysis is much more complex and nuanced. Our findings are based on interviews with a very specific group of Muslims: elderly Muslim women, first generation migrants, illiterate and socially isolated. Hence, we do not claim to have presented the singular Muslim view on the topic. Perceptions of younger Muslim generations on the topic might be different. As such, we acknowledge the possibility of Islamic positions which are (more) tolerant toward euthanasia. Two examples were found in our study. Given this, we take into account that adherents of one religion can perceive a righteous and pious way of life very differently, and that religious motives can play a (partial) role in their *approval* of euthanasia. In the same way, we acknowledge that the West as well is not a monolithic entity and that theological frameworks which are similar to those put forward by the interviewees in our study, are not strange to the Western world.

A few methodological limitations of the study should be noted. First, our sample size is rather small. Nevertheless, saturation was reached: no new elements came forward from further interviewing. Second, as the interviewer (first author) did not master Arabic, Berber, and Turkish and as the participants had a limited knowledge of Dutch, we had to rely on two experienced (female) interpreters, one of Moroccan origin (speaking Arabic and Berber), and one of Turkish origin (fluent in Turkish). We worked with one interpreter for each of the interview series, which maximized consistency in translation and reliability of the study (Twinn 1997).

Inevitably, bringing in their own perspective, both interpreters likely had an impact on our findings. Indeed, research shows that interpreters are not neutral transmitters of information (Freed 1988; Edwards 1998; Jentsch 1998; Kapborg & Berterö 2002; Liamputtong 2010). Their influence in the fieldwork, as active participants in the interview process, creating a "triple subjectivity" (the interview consists of interactions between the three subjects – participant, researcher, interpreter), must be acknowledged (Temple & Edwards 2002; Liamputtong 2010).

In order to capture this impact of the interpreters, interview data and their personal perspectives on it were regularly discussed with them. Due to the fact that they were member of the communities from which participants were drawn, the interpreters could function as cultural brokers, facilitating recruitment of participants and development of a trusting relationship with them, helping to acquire and maintain cultural sensitivity, and explaining specific cultural habits and religious convictions (Jentsch 1998; Liamputtong 2010). At the same time, the presence of the interpreter – as a member of the Muslim community – may have prevented participants from expressing personal viewpoints that they felt were intolerable in Islam.

Third, two participants (Ayten and Saida) expressed an opinion which clearly deviated from the majority view. We linked this to specific theological views and personal experiences (the loss of their husband). It is probable that personal confrontation with terminal illness is a determining factor in the way ethical issues at the end of life are approached, but it could not be concluded from this study, as we noted that another interviewee (Zohra) who had also been confronted with the terminal illness of her husband, voiced the normative Islamic (disapproving) stance on euthanasia.

Fourth, we explicitly chose not to recruit terminally ill patients for the study. Large-scale follow-up research, for instance among Muslim patients and their family members in palliative care settings, should explore the possible impact of personal confrontation with terminal illness on attitudes toward active termination of life in greater depth. Further research is needed to determine whether, among these patients, the role of religion in

approaching ethical dilemmas at the end of life diminishes and/or whether religious ideas, such as theological convictions about God, are conceived differently.

Fifth, as the situation of elderly first generation Muslim migrants in society differs significantly from that of younger generations – for instance in terms of cultural and language barriers – follow-up research should explore their attitudes toward the issue at hand. It would be particularly interesting as well to elicit the opinions of younger Muslim women, who tend to be less isolated from Belgian society than elderly first generation Muslim women.

In sum, Muslim views on the acceptability of active termination of life differ significantly from the dominant public opinion found in Western European countries. While in these countries an open attitude toward a right-to-die discourse is displayed, right to self-determination (at the end of life) is felt to be irreconcilable with Islam. Similarly to normative Islamic discourses on active termination of life, our qualitative empirical study among first generation female Muslim migrants (age 55+) in Antwerp (Belgium) shows a strong dismissive attitude toward active termination of life (voluntary euthanasia, assisted suicide, and non-voluntary euthanasia). In the same way, as the fatwas of the *muftis* base the prohibition against active termination of life on theological arguments, our interviewees based their viewpoints on the matter on a similar theological line of reasoning. Apart from the striking difference between dominant secular Western viewpoints on the matter that stress a person's absolute right to self-determination, and dominant Islamic perspectives on the topic that stress God's sovereignty in life and death, this study indicates an important, complex interplay between (religious) world views and ethical attitudes, and points to the danger of falling prey to a simplistic and monolithic approach to understanding both Islam and the West.

13 Non-Treatment Decisions: Perspectives of Elderly Female Muslims in Belgium

13.1 Introduction

In healthcare, trans-cultural patient-physician relationships have become an everyday reality. Increasingly taking care of patients having non-Western roots, healthcare professionals are challenged to provide care which is sensitive to the patient's cultural and religious background. Over the past few years, the need to provide culturally competent care has been increasingly addressed. Scholars indicated the importance of paying attention to effective communication in healthcare – which might be hampered by language barriers – as a prerequisite to render adequate care (Markova & Broome 2007; Dogan *et al.* 2009). Others pointed to cultural customs and traditions, for instance the central role of patients' family members (Lawrence & Rozmus 2001; Dogan *et al.* 2009) and sensibilities with regard to cross-gender interactions in healthcare (Dhami & Sheikh 2008; Padela & del Poz 2010). The lack of chaplaincy services in order to appropriately address religious and spiritual needs of non-Christian patients, for instance Muslims, was discussed (Gatrad, Brown & Sheikh 2004; Sheikh 2004; Abu-Ras & Laird 2011) as well as the necessity to pay attention to Muslim patients' ritual needs and religious duties, such as praying and fasting (Lawrence & Rozmus 2001; Sadiq 2008). Providing care which is sensitive to patients' culture and worldview entails taking a "context-sensitive approach" (Lützén 1997). Healthcare professionals and patients may hold different values and worldviews, which may have a significant impact on the way they deal with contemporary medical possibilities and the ethical dilemmas they bring forth.

Due to advances in medical sciences, more and more prospects for life-sustainment have been created. At the same time, these advancements furthered questions of the desirability and meaningfulness of (further) treatment. Aiming to create conceptual clarity with regard to non-treatment decisions, Broeckaert and the Flemish Palliative Care Federation developed a conceptual framework regarding treatment decisions in advanced disease (Broeckaert & Flemish Palliative Care Federation 2006; Broeckaert 2008; 2009b). In this typology three kinds of decisions with regard to (forgoing) curative or life-sustaining treatment are distinguished. First, the choice can be made to continue or initiate treatment aimed at recovery or life-sustainment (*initiating or continuing a curative or life-sustaining treatment*). Second, when treatment is no longer considered meaningful or effective, one can choose to withhold or withdraw treatment (*non-treatment decision*). Third, a patient can opt to refuse treatment (*refusal of treatment*).

Of course, whether further (life-prolonging) treatment is considered desirable is case-dependent. Moreover, patients (and their families) (might) have specific viewpoints on this, which may not only be influenced by medical facts, but also by cultural and religious perspectives. People observing the Muslim faith, for instance, might be cautious to take a decision which might contradict Islam. For most Muslims, being Muslim covers an all-encompassing way of life. In other words: they "incorporate their religion in almost every aspect of their lives" (Daar & Al Khitamy 2011, p. 61). Hence, for many Muslims their *religious* identity becomes visible in the way they behave in the *secular* realm of life. Their healthcare preferences thus may reflect their adherence to Islam. Being a good Muslim translates into acceptable Islamic behaviour in everyday life, even in the segment of healthcare. As such, a Muslim's decision to continue, initiate, withhold or withdraw treatment might be in an important way influenced by his/her religious convictions.

For non-Muslims born and grown up in a Western society this interference between the secular and religious sphere of life might be difficult to grasp. During the past decades, Western societies have undergone processes of secularization. As a consequence, religion has lost considerable impact, gradually becoming an individual and private matter. This tendency is completely in line with the autonomy discourse which is quite dominant in the Western world and which stands in sharp contrast with Muslims' stress on submission to God's will. For observant Muslims, living according to God's will is predominant over self-determination. For them, resignation to God's will and responsibility towards God is central (Sedgwick 2006; Platti 2008). As a result, individual Muslims' approaches of non-treatment decisions might differ from viewpoints which are dominant in the Western world, and caregivers must be aware of this. Given the fact that Muslims at present form the largest religious minority in the United States and in a lot of countries in Western Europe, they will increasingly appeal to Western healthcare. Therefore, we considered it important to elicit Muslim attitudes towards care for patients with a life-threatening illness. Is it conceivable for them to withhold or withdraw (life-sustaining or curative) therapy, and in which circumstances would this be allowed?

13.2 Methods

Since it is more probable that elderly people are more frequently appealing to medicine, we decided to elicit the attitudes of Muslim women aged ≥55 years towards withholding and withdrawing (life-sustaining or curative) treatment. The city of Antwerp (situated in Flanders, Belgium) (population number: ±500.000) houses an important number of people over the age of 55 of North-African (±4500) and Turkish (±2000) descent (Lodewijckx 2010), among them men and women who have lived in Belgium since

the 1960s-1970s. Proportionally, this amount is rather high in comparison to the number of elderly (≥60 years) people of Moroccan (±5000) and Turkish (±6000) origin living in Flanders (Lodewijckx 2010). From the 1960's onward, young Turks and Moroccans were employed in Belgian industry, for instance as miners and steelworkers. Although intending to return to their home country after a few years of employment, most of them settled in Belgium permanently, together with their family (Lesthaeghe 2000a; Reniers 1999; 2000; Surkyn & Reniers 1997). We did snowball sampling among these guest workers' spouses. Given gender segregation in Islam and the female sex of the interviewer (1st author), only *women* were interviewed. Thirty women (15 Moroccans and 15 Turks) participated in the study and they agreed with recording the interview. Semistructured in-depth face-to-face interviews were done following Grounded Theory methodology (Glaser & Strauss 1967; Strauss & Corbin 1998). On average, an interview took 75 minutes. Every participant was interviewed separately in a quiet location (in the interviewee's house or in a room made available by a local organization). As the participants did not speak (well enough) Dutch and the interviewer did not sufficiently master the mother tongue (Turkish/Arabic/Berber) of the participants, the interviewer was assisted by two experienced interpreters. One interpreter fluent in Dutch and Turkish assisted during the interviews with the elderly Turkish women, and the other interpreter, speaking Dutch, Arabic and Berber helped out with the interviews with the elderly Moroccan women. As soon as possible after having concluded the interview, it was transcribed verbatim and coded. Making use of software for qualitative data analysis, we added codes to the data and identified key concepts. Through constant comparisons, categories were determined and interrelated. The outcomes of the study were frequently discussed with the research supervisors. Interviewing continued until the moment no new insights were yielded through further data collection and analysis. At that point, theoretical saturation was reached.

The semistructured questionnaire covered questions regarding demographic information (for instance, migration history and family situation), religious convictions and practices, and attitudes towards end-of-life treatment decisions. The interviewees' attitudes towards (forgoing) curative or life-sustaining treatment were elicited making use of hypothetical cases, which were generated on the basis of the clear definitions for each of the treatment decisions (initiating or continuing a curative or life-sustaining treatment; non-treatment decision; refusal of treatment) offered in Broeckaert's conceptual framework. The cases are mentioned in Figure 1. The results are illustrated with interviewees' quotes. In order to assure confidentiality, pseudonyms are used.

Figure 1: Hypothetical cases

Case 1: Initiating or continuing a curative or life-sustaining treatment

There exists a cancer treatment that may prolong life with a few weeks. This treatment has many negative side-effects. Should a physician opt for this treatment?

Case 2: Non-treatment decision

An unconscious patient is artificially kept alive (respirator, artificial nutrition and hydration). The patient is in a deep and irreversible coma. Should the devices be switched off so that the patient dies? Who should decide about that?

Case 3: Refusal of treatment

A physician has told his/her patient that chemo therapy may cure his/her cancer. Has the patient the right to refuse this treatment, even if he/she knows he/she will die soon if no treatment is administered?

13.3 Results

13.3.1 Participants' demographic information

Thirty observant Muslim women of Turkish and Moroccan descent, living in Antwerp (Belgium), were prepared to cooperate. They were aged between 55 and 73 years. The Turkish participants (n=15) were born in western, northern, and central Anatolian provinces, and had Turkish as their mother tongue. The Moroccan interviewees had their roots in northern Morocco. Their mother language was Tarifit, a Berber language (n=8) or Arabic (n=7). All interviewees migrated to Belgium between the early 1960s and early 1980s, joining their husbands who worked as 'guest workers' in the Belgian (mining) industry. At the time of the interview, 16 participants were married, 5 were divorced and 9 were widows. Most participants were uneducated and illiterate, and were never employed in Belgium. After their arrival in Belgium they stayed at home, taking care of the household and the children. Among the 30 women in the sample, the number of children varied between 0 and 14.

13.3.2 Participants' attitudes towards withholding and withdrawing treatment

13.3.2.1 Case 1: Initiating or continuing a curative or life-sustaining treatment

Analyzing the interviewees' reactions to the case, differences between the responses of the Turkish and the Moroccan participants attracted immediate attention. While for the Moroccan participants the duty to opt for treatment was almost absolute, some Turkish interviewees stressed the importance of taking case-specific circumstances into account. Three Turkish participants were of the opinion that treatment in the given case was meaningless. For them, the unbearable suffering of the patient outweighs the importance of treatment.

> When there are a lot of side effects… And he will die in the end… When there are side effects, for instance pain, it's better not to do it. […] When he has a lot of pain, and if the medication does not have any effect… (Mehtap - Turkish)

> If it is really difficult, if there are a lot of heavy side effects, I would not choose for the treatment. If it causes a lot of pain, I don't want the patient to suffer even more. […] When the patient has a lot of pain, it [treatment] is meaningless. (Hülya - Turkish)

Özlem emphasized that preserving quality of life for a patient is crucial. On the other hand, she said, one should never loose hope. Saida, of Moroccan origin, as well acknowledged that treatment can be rather a burden for the patient. At the same time she underlined that people should be hopeful and should try to recover by all means.

> It's very delicate. Having faith is also important. It's ambiguous. On the one hand, yes, with therapy a patient can live a few weeks longer. But on the other hand, these side effects… It's better to leave him. It's ambiguous. It's a difficult, a very difficult question. (Özlem - Turkish)

During the interviews it was regularly explained that taking care of one's body is a commandment of Allah. Therefore, for most Turkish and Moroccan interviewees treating the patient in the case presented to them was an evident choice. Additionally, they expressed the view that in the given case the physician should take his/her task seriously. For them, a physician's task is to help people out and to fight for life.

> She has to be treated. You have to do what Allah says: 'seek cure'. If you choose for treatment, maybe you will recover, maybe you will die, but you have to do it. (Yamina - Moroccan)

> Yes, he must give her medication. He must help her. Yes, he can give her medication to help her, even for only a few weeks. Yes, even for only two, three weeks, she has to live as long as possible. (Hanan - Moroccan)

> We would say: 'do it, doctor', and we would await the outcome. You never know... The doctors have taken an oath, they have to fight for life. (Kezban-Turkish)

Considerable trust was put in doctors: during the interviews the physician's erudition was frequently underlined. As such, Jamila, of Moroccan origin, and Bahar and Handan, both of Turkish descent, preferred to leave decisions of treatment in physicians' hands.

> I have no opinion about it. It's the decision of the doctor. The doctor will know it better. The doctor should decide about that. (Handan - Turkish)

> I cannot answer that. I don't know if... I cannot give an opinion about what a doctor should do. The doctor is the boss. [...] He is learned. He knows what he must do. I don't know that. I go to the doctor and I take everything he gives me. (Jamila - Moroccan)

At the same time, the interviewees underlined the physician's limitations, standing in sharp contrast with God's omnipotence. They explained that medication and doctors are created by God as *possible* remedies for illness, and that only God decides whether treatment will be effective; only Allah decides what will be the outcome of undergoing therapy.

> The doctor cannot do much about it. God knows it. God will prolong life, or you die. God knows it. The doctor will try to prolong the life of the patient, but God decides about it. (Lale - Turkish)

> When the moment has come... You are born and you will die. It's written upon birth. And then, the doctor cannot help much. When the moment has come, even with therapy, that person will die. (Züleyha - Turkish)

> Yes, a doctor always has to give medication, he has to treat you always, but maybe it helps, maybe not. If Allah wants, death comes, whether or not you take medication. (Yamina - Moroccan)

Even more than putting trust in physicians, reliance on God was highlighted. This unconditional trust in God did not imply fatalism or passivity with regard to illness.

Though death cannot be warded off – the participants believed that God predetermines each individual's moment of death – the majority of the participants, including all Moroccan interviewees, were of the opinion that every available means should be used to treat people until death sets in.

> He must try to help, but it is only God who decides if he will die. Yes, he must, he must help her until death comes, until the hour of death. (Fatiha - Moroccan)

> When the moment has come, life cannot be prolonged. When the moment has come, the patient dies. (Pinar - Turkish)

13.3.2.2 Case 2: Non-treatment decision

Again, differences were noticed between the reactions of the Turks and the answers of the Moroccans. One third of the Turkish respondents were in favour of switching off the devices in the case presented here. They mentioned two arguments. First, they explained that they would rely on the physician's diagnosis, drawing attention to his/her erudition. When doctors judge that a patient's coma is irreversible, there is no reason to continue treatment. Second, some participants underlined the patient's lack of quality of life.

> He's lying there like a dead person. When there is no more hope, then the machine can be switched off. (Lale - Turkish)

> They are allowed to switch off the machines, because his life is over. He is in an irreversible... It's over, his life is over. He only lives through the machines. It's painful for that person. [...] He's like a living dead. And if it takes longer, it's not necessary. (Gamze - Turkish)

Mehtap based her approval of discontinuing treatment in the case of an irreversible coma on the opinion of a religious scholar (*hoca*). According to Mehtap, this *hoca* once said that withdrawal of treatment in this case is not a sin.

> He will never recover. He will never regain consciousness. [...] And I asked the *hoca*. She said it is not a sin. So, it can be removed. (Mehtap - Turkish)

Hesitation with regard to the presented case was also perceived among some Moroccan participants. Saida was uncertain about the case, referring to the agony of her husband who died a few years ago suffering from a heart condition. Jamila, Yamina and

Fatiha hesitated to express an opinion about the case, underlying the physician's expertise. They stressed the erudition of the physician, in contrast to their own illiterateness. Farida explained that only Allah knows the outcome. Therefore, she felt uncomfortable with giving her opinion about the case.

> He [the doctor] is the boss, if he wants to switch it off, he switches it off. [...] He [the patient] is in the hands of the doctor, the doctor does what he wants. (Fatiha - Moroccan)

> I don't know, only Allah knows. [...] Yes, only Allah knows. There are people who wake up and there are people who don't. (Farida - Moroccan)

Nevertheless, in the end all Moroccan participants – except for Saida and Farida – agreed that discontinuing treatment in the case presented here is ***not*** allowed. Despite some tolerant voices towards withdrawal of treatment, this denunciation of switching off devices in case of irreversible coma was also predominant among the Turkish interviewees. Among the Turkish and Moroccan interviewees, several arguments were offered to substantiate this position. First, withdrawal of medical devices in the presented case was considered a life-shortening act. The interviewees explained that a physician murdering a patient could not be tolerated.

> He is still alive and you switch off the machines and he dies. That's murder. (Zohra - Moroccan)

> If you do that, you are a murderer, because you let him die. You killed him. (Bahar - Turkish)

This act was considered "haram", forbidden according to Islam, and therefore irreconcilable with living a pious Islamic life. Next, the interviewees argued that taking the decision to withdraw treatment equals with intervening with God's will. They explained that everything in the world and in a person's life happens according to God's predetermined plan. Allah decides upon life and death.

> Among Catholics or Belgian people, it happens, switching off machines or giving a lethal injection. For us, in Islam it is forbidden. It's ***haram***, it's not allowed [...] In our religion, it does not happen. They are not allowed to switch off the machines. In our religion, life has to be ended by Allah, not by human beings. (Mariam - Moroccan)

> I cannot say to the doctors 'switch off the machines', because we always wait until the time [to die] has come from God. (Pinar - Turkish)

Aziza and Zorah, both of Moroccan descent, explained that only God "kills". The participants who disapproved of withdrawal, added that human beings have to put unconditional trust in God's plan. As human beings have limited knowledge, Allah's plans are hidden from them, they argued. As such, human beings cannot decide to end life. In such situations, the participants explained, it is essential to be hopeful, to rely on God and to reconcile oneself to God's decision. Whether the patient will regain consciousness or whether he/she will die, ultimately is God's decree, the participants explained.

> No, the doctor cannot switch that off. Only God knows when he will die. The doctor cannot switch off the machine. Maybe he wakes up, you never know. You never know that there will be a miracle. It's not allowed. (Mina - Moroccan)

> Maybe God will wake him. You may never give up hope. (Dilek - Turkish)

The interviewees again contrasted the physician's limited knowledge with Allah's omniscience. They argued that putting forward a life prognosis is entering God's domain. For them, the physician does not have the authority to intervene with a patient's life on the basis of his/her presumed unfavourable prognosis. They reported that Allah is the highest doctor. The earthly doctor is 'only' a "scientist", who should not be equalled to God, Aziza underlined.

> I have experienced this with my husband, he was in a coma as well, during twenty days. And the doctor said 'he only has two hours to live. It's irreversible.' Like in the case, it was irreversible. We had arranged everything for the funeral, because he would die. And in the end, he did wake up. And he went to Morocco and Mecca. Yes, he still lived for five years. Yes, the day [of death] was not yet there. Therefore, the doctor does not have the right to switch off the machines. (Hakima - Moroccan)

13.3.2.3 Case 3: Refusal of treatment

Most (Moroccan and Turkish) participants underlined that it is essential to choose for treatment. Again, they referred to a patient's obligation to seek cure, and they expressed the view that taking care of one's body is a divine commandment. Farida, of Moroccan descent, mentioned the famous saying of Prophet Mohammed: "For every disease there is a cure". Therefore, the interviewees explained, a passive attitude towards illness is not tolerated: patients should consult physicians, who are created by God as possible means for cure.

> He has to take the medication, because he may not give in, he has to be treated. Allah has given us a message: 'you should take care of yourself'. [...] Only God knows when you die. Therefore, you have to take your medication, you have to seek treatment. (Mina - Moroccan)

Additionally, anew the interviewees explained that physicians are limited. Although ill persons should seek means (doctors, medication) to be cured, they should also acknowledge that only God decides what will be the outcome of taking therapy. Again the physician's (restricted) medical knowledge was contrasted with God's omnipotence and omniscience. They explained that in the end a patient's fate is determined by Allah. Therefore, for the participants seeking cure should go hand in hand with trust in God.

> You can do everything, when the moment of death has come, then it's there, whether medication is given or not. [...] It's difficult to speak out about death, when death will come. It's not in our hands. When medication is given, maybe she will recover, if Allah wants it, and maybe she will die. (Fatiha - Moroccan)

> Maybe with chemotherapy the patient will live longer, but only God knows it. God will decide when the patient's life will come to an end. But you have to do everything to recover, you have to do everything. (Ferhunde - Turkish)

Moreover, for the interviewees renouncing therapy equals being impatient. They explained that a patient who decides to refuse treatment does not have faith in God, as he/she waives the divine commandment to seek cure. They saw it as a sign of disobedience to Allah.

> If they want to die, they turn away from God. That's my opinion. It is like not having faith in God, like taking the right in their own hands. (Hanan - Moroccan)

> She has to take the medication. When she dies, Allah will tell her: 'why didn't you do that, why didn't you do what I..., why didn't you have patience? I have given you an illness to be patient, to test your patience'. (Mariam - Moroccan)

> When she chooses not to be treated and she dies, she does not die as a Muslim. For instance, a diabetic goes to the doctor and says 'I feel sick', and the doctor says 'it's not a good idea to follow Ramadan'. And yet, she fasts,

> and the next day she dies. Then, she didn't die as a Muslim. She didn't listen. (Aziza - Moroccan).

At the same time, some Turkish and Moroccan participants expressed no explicit preference for treatment in this case and recognized a patient's personal choice. Two arguments were mentioned. First, a patient has the right to decide and should certainly not be coerced, and second, some participants expressed the view that patients who choose to renounce therapy, leave their fate in God's hand and are not to be blamed.

> The patient can choose. When it's enough, he has the right to say so. Maybe the patient has had enough, and then he says 'no thanks, I don't need it'. (Pinar - Turkish)

> He is not obliged to choose treatment, because Allah has created us, and he kills us. [...] It's not the doctor who cures, it's Allah. There are people who do not want to choose for treatment. If Allah cures us, it's okay, and if he does not cure us, then we die. (Yamina - Moroccan)

Yet, most participants considered it very unlikely that a patient would refuse (curative) treatment. Most people show a strong desire to live, and would not choose to give up hope.

> I don't think a lot of people refuse treatment. I don't think so. Refusing medication, I don't think so. Most people want to try everything for their health. (Saida - Moroccan)

> It's possible. Because chemotherapy is really heavy. [...] When the patient had enough, he is allowed to say so. But still, as a human being, you always fight for life. (Lale - Turkish)

> No, there is hope and the patient may not refuse the treatment, because this world is a world of hope. Maybe the chemotherapy will cure him. (Bahar - Turkish)

13.4 Discussion

During the past few decades rapid advances have occurred in Western medicine. Increasingly, aggressive and costly life-sustaining therapies for critically ill patients have been made available. The increasing possibilities of life-sustainment stimulated debates on medical futility. Another factor which fostered this discussion was the increasing emphasis

on patient autonomy and informed consent, marking a shift from a paternalistic model of medical decision-making to a consumer-driven model, accentuating a patient's right to self-determination (von Gruenigen & Daly 2005). The increasing stress on patient autonomy became not only evident in patients' right to refuse treatment, but also in their demands for aggressive interventions (Moratti 2009). From the 1980s onward, medical futility became a hot topic in biomedical publications, that attempted to clarify its definition and meaning (Schneiderman, Jecker & Jonsen 1990; Truog, Brett & Frader 1992; Helft, Siegler & Lantos 2000; Burt 2002; Kasman 2004; Bailey 2004; Burns & Truog 2007; Moratti 2009). Soon, futility became a controversial issue and its "legitimacy as a rationale for limiting treatment" (Truog, Brett & Frader 1992, p. 1560) was discussed (Moratti 2009). Already in the early 1990s, Truog, Brett and Frader (1992) argued that the promise of an objective conceptualization of futility could not be fulfilled, and that perspectives and values of patients and/or surrogates should be clarified when dealing with interventions regarded as futile. As such, other authors as well claimed that futility is not a value-free concept, which "cannot be defined in purely descriptive terms" (Löfmark & Nilstun 2002, p. 115). Indeed, judgments about the desirability and meaningfulness of treatment are very delicate decisions which not only entail "an assessment of physiologic benefit and burden", but are "also influenced by personal characteristics of both patients and physicians" (von Gruenigen & Daly 2005, p. 643), thus involve very subjective value judgments (Moratti 2009; Bailey 2004). In this sense, Broeckaert (2009) affirms, a treatment is considered to be futile when in the given circumstances it is no longer considered *effective or meaningful.* In the same way, Jecker (1995) pleads for taking patients' subjective experience of illness into account, apart from taking a solely physiologic approach of end-of-life decisions.

Several authors have shown that contemporary good practice in medicine with regard to decisions to withhold and withdraw treatment, entails a focus on communication and negotiation with patients and their families (Helft, Siegler & Lantos 2000; Burns & Truog 2007; Löfmark & Nilstun 2002; Curtis & Burt 2010). Thus, "in the event that a patient or family persistently requests a treatment that the health care team regards as futile, a process of sensitively negotiating the conflict should occur" (Jecker 1995, p. 289). In the same way, Curtis and Burt (2010) plead for shared decision-making as the ideal physician-patient/surrogate relationship. Specifically, McCabe and Storm (2008) argue that early, open en ongoing communication with patients about end-of-life care should ease the transition from cure-oriented therapy to symptom-oriented palliative care.

In our study among a very particular subgroup of Muslims in Antwerp (Belgium) – namely: elderly first generation female Muslim migrants, of very humble descent, who are uneducated and illiterate and who live quite isolated from Belgian society – the almost absolute stress of the participants on seeking cure and not giving up hope, could provoke

considerable debate on medical futility. Hence, in concrete Western healthcare settings today, discussions or conflicts about the meaningfulness of a particular treatment between healthcare professionals and Muslim patients are likely to arise. Indeed, several empirical studies in Europe and the United States have shown that in contemporary healthcare limitation of life-sustaining treatment is widespread (Prendergast, Claessens & Luce 1998; Deliens *et al.* 2000; Esteban *et al.* 2001; Ferrand *et al.* 2001; Sprung *et al.* 2003; van der Heide *et al.* 2003; Georges *et al.* 2006; Jensen, Ammentorp & Ørding 2011). In contrast, when confronted with hypothetical cases, the overwhelming majority of our interviewees vehemently objected to withholding and withdrawing treatment. Similarly, empirical studies in Turkey, Lebanon and Oman show a rather reluctant attitude to withdrawal of life support, which also may have to do with the influence of religious (Islamic) viewpoints (da Costa, Ghazal & Al Khusaiby 2002; Iyilikçi *et al.* 2004; Yazigi, Riachi & Dabbar 2005).

The very specific rationale the participants of our study provided for opposing limitation of treatment, shows that their own frame of reference differs significantly from a discourse which tends to stress patient autonomy, which is fairly dominant in the Western world. The interviewees' predominant opposition to forgoing life-sustaining therapy and their emphasis on treatment (with every possible means) can be understood from their shared theological framework. First, almost every participant referred to the divine commandment to take care of one's body. Hence, seeking cure and accepting treatment is a sign of faith in and obedience to God. In the same way, the physician's task was conceived of as helping out and fighting for life. Next, the physician's limitedness was contrasted with God's omnipotence and omniscience. As such, apart from seeking doctors' expertise, the interviewees underscored, patients must rely on God and put trust in God's predetermined plan. Therefore, as God already determined the life span of human beings, the majority of the participants emphasized that it is essentially *haram* (forbidden) to withdraw a coma patient's life-sustaining measures, perceiving it as a life-shortening act.

These data show that strong demands for treatment may be influenced by patient-specific and case-related factors, such as religious convictions (Brett & Jersild 2003), and hence confirm that judgments about medical futility are often not value-neutral. Islam's huge stress on the importance of providing life-support resembles the Jewish emphasis on *pikuah nefesh* (life preservation), and (Orthodox) Jews' reluctance towards withholding and withdrawal of treatment (Alibhai & Gordon 2008; Baeke, Wils & Broeckaert 2011d). The interplay between religion and decisions to forgo treatment has been confirmed by other empirical studies (Sprung *et al.* 2007b; Zier *et al.* 2009). Having conducted an empirical study among elderly first generation Moroccan men in Antwerp (Belgium), Van den Branden draws (2006; Van den Branden & Broeckaert 2008) comparable conclusions. Very similar to our empirical findings, Van den Branden's participants substantiated their

position on withholding and withdrawing life-sustaining treatment with theological arguments. Their central line of thought was that Allah's and human beings' actions go together. On the one hand, it is imperative for human beings to seek treatment and cure, seeing the Islamic faith in the sanctity of life. On the other hand, faith in Allah's omnipotence and omniscience puts the efforts of human beings and physicians into perspective. In the same way as our interviewees did, the participants in Van den Branden's study argued that Allah is the true healer of human beings – the physician is only God's instrument – and that Allah decides upon the result of a therapy. Moreover, in God's inscrutable and inalterable plan with creation, the life span of every human being has been determined. As such, the interviewees stressed, being confident in physicians' expertise must go together with reliance on Allah.

Like in our study, not all participants in his study put unconditional stress on keeping up life-support. Analogous to our study, some participants were (hesitatingly) positive with regard to withdrawing life-sustaining treatment in case of a patient in an irreversible coma. The principal argument offered was trusting the physician's expertise, which might reflect a strong reverence for doctors and a paternalistic physician-patient attitude which are common in Islamic context (Atighetchi 2007; Sachedina 2009). In the same way, some participants – in the study of Van den Branden as well as in our study – underscored a patient's right to refuse treatment, leaving one's fate in God's hands. Strikingly, in our study exceptional pro-withholding and pro-withdrawal attitudes were predominantly found among (female) *Turkish* participants, mentioning for instance quality-of-life arguments, while our (female) *Moroccan* participants were more strict. Aksoy found a tolerant attitude among the Turkish people to withdrawal of life-support, given the strong belief in predestination, thus the fact that "extra efforts at the terminal stage of illness may be interpreted as a fight against destiny" (2005, p. 190). As we found an equally strong belief in predestination among our Moroccan interviewees, for our study this argument is insufficient, as it does not explain the dissimilarities we found between the reactions of the Moroccans and the Turks. A possible explanation could be that, during their stay in Belgium, our Turkish interviewees might have been more influenced by Western culture, which may be evident from the quality of life arguments which sometimes popped up during the interviews. In contrast to our *female* Moroccan participants, Van den Branden's *male* Moroccan interviewees seemed to be less rigorous and more nuanced. Possibly, the degree of mosque attendance, contact with/isolation from the peer group and Western society might play a role. Our female interviewees have always lived rather isolated from society – most of them have always been housewives, barely being able to speak and understand Dutch. In contrast, elderly first generation male Muslims were employed for many years in Belgian industry, thus having lived less isolated from Western culture. Moreover, while men may hear different, nuanced voices among peers and in imams'

sermons and explanations, women – who are not obligated to attend mosque – may be more isolated from peers and may have less opportunity to acquiring sound religious knowledge. Which factors precisely contribute to differences between Moroccan men and women on the one hand, and female Moroccans and Turks on the other hand, needs further investigation.

In international English language literature on Muslim medical ethics we find less rigorous viewpoints with regard to non-treatment decisions. Hence, while our empirical findings of the ethos observed among a very particular group of Muslims (female Turkish and Moroccan elderly first generation Muslim women in Antwerp, Belgium) might suggest that the medical futility debate is (rather) absent in Islam, this could be a misconception. Publications of Islamic organizations and authors, reflecting normative Islamic standpoints, show that (resistance to) medical futility comes up for discussion in Islam.

In the Islamic Code of Medical Ethics, the Islamic Organization of Medical Sciences (IOMS) states that forgoing life-sustaining treatment can be permissible under strict circumstances, since a physician's task is not to maintain the process of dying, but the process of living. Therefore, the code argues that it is futile to keep a patient in a vegetative state "if it is scientifically certain that life cannot be restored" (Islamic Organization of Medical Sciences 1981). The 2004 Islamic Code of Medical and Health Ethics (Islamic Organization of Medical Sciences 2004) maintains that a treatment (including artificial respiration) which is considered to be "useless" should not be started or continued. In the same way, the Islamic Medical Association of North America (IMANA) endorses the possibility to withhold and withdraw life-support, in case the inevitability of death (of a terminally ill or PVS (persistent vegetative state) patient) is determined by a team of physicians. According to IMANA (2005) mechanical ventilation can be withdrawn, but comfort measures, such as nutrition, hydration and pain control, should be provided.

A very similar position is put forward by Sachedina (2009), who asserts that life-support can be turned off in case physicians determine that death is inevitable. For him, "death-delaying" "futile" and "disproportional" treatment are against the benefit of the patient and should not be administered when there is no hope of recovery, on the condition that the physician's intention is sincere, and after well-informed consultation between all parties involved in the patient's treatment (Sachedina 2005; 2009). As such, Sachedina affirms that withdrawal of futile treatment, allowing death to take its natural course, is not contradictory to Islam. In the same way, Gatrad and Sheikh (2001; 2002) state that artificial prolongation of life which does not guarantee a reasonable quality of life, is disapproved by Islam. At the same time, they recognize that withdrawal of treatment (from Muslim patients) is a very difficult medical-ethical matter. They stress that a patient should not be deprived of nutrition and hydration, and that in Islam the intention of the

physician is of utmost importance: aiming to reduce suffering is acceptable, willing to hasten death is not (Gatrad & Sheikh 2001). Hedayat and Pirzadeh (2001) limit the acceptability of withholding and withdrawing treatment to a brain-dead patient, which seems to be a very strict criterion. At the same time, they affirm that in case a treatment does not improve a patient's condition or quality of life, it can be refused. Indeed, today nuanced and positive attitudes to withholding and withdrawal of life-support – willing to avoid the administration of futile treatment – are found among Islamic organizations and authors.

Rispler-Chaim (1993), who analysed (Arabic), mainly Egyptian, fatwas issued in the 1980s and 1990s, found a more strict position in the source material, identifying withholding and withdrawal of medical treatment with "passive euthanasia" (Rispler-Chaim 1993, p. 95), stating that all forms of euthanasia are viewed as murder in Islam, and finding that "anyone who was ever consulted and opined in favor of euthanasia, all the more the doctor who disconnected the life-sustaining machine and the relative who signed the authorizing papers, are guilty of the same crime – murder" (Rispler-Chaim 1993, p. 98). Van den Branden (2006), having reviewed English language Sunni views on non-treatment decisions pleads for a very nuanced approach of Muslim standpoints on the matter. He stipulates that in most cases which approve of a non-treatment decision, strict conditions are stipulated (such as: the patient is brain dead or almost dead; the patient cannot recover or get better; the patient is terminally ill; artificial nutrition/hydration cannot be stopped). From his review, he concludes to have observed a dominant disapproval of withdrawing/withholding medically effective treatment. Atighetchi (2007), having analyzed more recent contemporary fatwas and standpoints of Islamic organizations (such as IOMS and IMANA), comes to a similar conclusion. He discerned a clear distinction between deliberatcly terminating life and letting a patient die, and hence, a more tolerant attitude towards withholding and withdrawal of medically ineffective treatment.

The attitudes towards non-treatment decisions found in contemporary Muslim literature, reflecting normative Islamic viewpoints, seem to be more open than the dominant ethos discovered among the specific subgroup of Muslims interviewed in our study. Yet, both lines of reasoning show similarities. Both differ significantly from secular approaches to the topic which are fairly dominant in Western medicine. From our analysis, we endorse the view of Van den Branden (2006) that when raising the issue of non-treatment, normative Islamic views often stick to the question of medical effectiveness, while leaving the factor of meaningfulness behind. However, we also think that this conclusion has to be nuanced, taking references to patients' quality of life – which we found in the reviewed literature and among some of our participants – into account. At the same time, we recognize that Islamic acceptance of withdrawing (medically effective)

artificial feeding would be rather exceptional – in contrast to secular Western viewpoints and practices (Groenewoud *et al.* 2000; Bosshard *et al.* 2005; Buiting *et al.* 2007; Jones 2010) – seeing that (normative) Islamic views tend to classify providing artificial food administration as part of basic care and not as a medical treatment.

A second similarity between the ethos detected in our empirical sample and the Islamic standpoints found among Islamic organizations and authors, is that perspectives on ethical discussions in healthcare are often framed theologically. This stands in sharp contrast to secular autonomy discourses which are very popular in Western medicine. Their discussions of the acceptability of particular ethical discussions in healthcare are not isolated from important theological views on human beings' status and role in creation, contrasting for instance the limitations of humans with God's omnipotence. Therefore, reference to absolute human autonomy and right-to-die discourses are very unusual in Muslim discussions. Hence, pro-withholding and pro-withdrawal reasoning are usually not based on autonomy arguments, such as a patient's right to decide about his/her life and body, but are contextualised with religious convictions, such as the exhortation to show respect for the living person, the encouragement to patiently accept death and the belief that a person's predetermined life span is part of Allah's inscrutable plan (Sheikh & Gatrad 2008b; Brockopp 2002; 2003a). Remarkably, a very similar theological line of reasoning popped up very frequently during the interviews in our study, often to substantiate a divergent opinion which stressed the (almost) absolute importance of keeping up life-support.

While we uncovered similarities between normative Islamic viewpoints and the dominant perspectives found among our interviewees, we underscore that the latter uttered claims which were less substantiated and nuanced. This can be ascribed to the specific characteristics of the interviewed group. All interviewees were elderly Muslim women (age ≥55) who have been living in Belgium for decades, yet quite isolated from Belgian society. While their husbands went out to work, they took care of their children and household. Due to this focus on family obligations, they had only scarce time to participate in social life, that is to have contact with peers and with Belgian society in general. This isolation was strengthened by the fact that most of them were of very humble descent, uneducated and illiterate, and unfamiliar with the Dutch language.

Our study conveys that for healthcare professionals it is essential to take into account specific sensibilities in the care for a Muslim patient (Ilkilic 2002). First, they should take into account that very specific underlying theological viewpoints may play a role in deciding about the acceptability of withholding and withdrawing life-support. Second, Muslims might be reluctant to disclose a fatal diagnosis to a gravely ill patient, given the Islamic stress on maintaining hope (Gatrad & Sheikh 2002), thus in order to

protect the patient from emotional harm (Buken 2003; Guven 2010; Atighetchi 2007). As such, the transition from cure-oriented therapy to symptom-oriented palliative care may be hindered. Moreover, the protective attitude of the Muslim community and (extended) family to the gravely ill may cause healthcare professionals to be confronted with considerable involvement of Muslim patients' family members in medical decision-making (Lawrence & Rozmus 2001; Atighetchi 2007; Sachedina 2009). As such, decisions about medical futility are two-levelled, as they are often not only based on medical effectiveness, but as well on what is considered meaningful for that particular patient and his/her relatives. In other words, sticking to a solely physiologic approach in judgments about medical futility often does harm to a sincere and adequate provision of healthcare, as it constitutes a neglect of the individual patient's value judgments and his/her subjective experience of illness.

Apart from the importance of taking specific sensibilities into consideration when caring for Muslim patients, caregivers must be aware of the variety found in Islam, for instance due to different cultural backgrounds or specific circumstances. There is no such thing as one single Islamic ethical tradition; diversity is recognized as being part of Islamic ethics, given its casuistical nature. Hence, Islam "considers cases, and in its normative pronouncements leaves space for the particulars of a situation to be inserted, and perhaps to modify the finding" (Reinhart 2003, p. 218). As such, fatwas (legal opinions) on one particular issue may vary significantly, as they depend on the specific situation described by the individual Muslim who seeks moral guidance (Brockopp 2003c). In this way, Islamic ethical guidance wants to respect a "balance between general rules and individual circumstances" (Brockopp 2008, p. 7). Islam's flexibility and case-oriented nature is also clear from the importance attributed to the principle of 'necessity allows the prohibited' in its ethical reflection, which entails that in cases of dire need and emergency it is permitted to forgo Islamic law (Padela 2006; Atighetchi 2007). The diversity within Islam must urge caregivers to refrain from a stereotypic approach of Muslim patients, and to get acquainted with each individual (Muslim) patient's perspectives, as concrete medical-ethical decisions are influenced by various specific personal factors (faith, culture, personal experiences, background, emotions, etc.).

Limitations of our exploratory study need to be acknowledged. First, the sample size of the qualitative empirical study is rather small. Yet, interviewing continued until the moment no new insights were yielded through further data collection. At that point, theoretical saturation was reached. Second, in order to complete the interviews successfully the interviewer sought assistance of two experienced interpreters, given the fact that the interviewer and participants did not master each other's mother tongue. Both interpreters (one of Turkish and one of Moroccan origin) were member of the research communities.

As such, they could function as cultural brokers, facilitating recruitment of participants and acquirement of cultural sensitivity, helping the interviewer to understand specific religious convictions and cultural customs (Jentsch 1998; Liamputtong 2010) As several studies show that interpreters are not neutral translators (Freed 1988; Edwards 1998; Jentsch 1998; Kapborg & Berterö 2002; Liamputtong 2010), it should be acknowledged that both interpreters inevitably influenced the findings of the study, bringing in their own perspectives in the fieldwork. Third, situational research in a concrete healthcare setting, among critically ill Muslim patients and their families could shed another light on the matter at hand. In this way, the impact of personal confrontation with terminal illness could be scrutinized. Fourth, (possible) differences between male and female Muslim viewpoints on the topic could be investigated in greater depth. At the same time, given the fact that elderly first generation female Muslim migrants tend to live rather isolated from Western secular society, which might be an influential factor in their chiefly reluctant and opposing attitude to non-treatment decisions, it would be interesting to look into opinions on the matter of younger generations of Muslims born and/or grown up in the West.

13.5 Conclusion

In conclusion, the analysis of Muslim views on the acceptability of withholding and withdrawing life-sustaining treatment uncovers that contemporary choices in healthcare often constitute very delicate and complex medical-ethical decisions, in which multiple factors have to be kept in mind. Our findings support the assertion that medical futility is not a value-free concept. Providing adequate care entails not only sticking to medical facts, but also paying genuine attention to values and perspectives of patients and their relatives. Hence, our analysis confirms that the medical futility debate is often two-levelled. Whether further treatment is desirable is not only dependent on its effectiveness, but also on its meaningfulness. Indeed, every patient brings in his/her own specifics, hence his/her particular frame of reference when dealing with health decisions. Our data suggest that among Muslims a theological framework is quite dominant when dealing with specific medical-ethical dilemmas. This frame of reference, stressing submission to God's will, stands in sharp contrast with a secular framework which underlines an individual's right to self-determination. Healthcare professionals might not be familiar with this interference of the religious and secular realm of life, i.e. the huge impact of religious convictions on everyday life. Indeed, for many Muslims it is evident that their faith provides guidance in all aspects of life. The increasing plurality of religions and cultures in present-day Western society urges caregivers to pay considerable importance to effective communication, to clarify the value-system of their patients, to develop contextual sensitivity and therefore, to acknowledge that a value-neutral approach of non-treatment decisions is a myth. At the

same time, clinicians must be kept from the pitfall to approach Muslim patients in a stereotypic way.

14 Conclusion

In the second part of the dissertation, we examined Islamic perspectives on concrete ethical dilemmas in end-of-life care. More specifically, we focussed on a presentation and discussion of the data obtained from our small-scale, exploratory qualitative empirical study conducted in the Turkish and Moroccan Muslim communities of Antwerp (Belgium). In the general introduction of this dissertation it was explained that we did not assume it useful to give in our text an overview of Islamic end-of-life ethics in general, given the fact that this overview is already given in the dissertation of dr. Stef Van den Branden (2006), who extensively looked into normative (Sunni) Islamic views on ethical dilemmas in end-of-life care. Still, in the discussion section of the chapters we confronted our participants' way of thinking with normative Islamic perspectives.

Thus, this part particularly focussed on a reconstruction of the way of thinking of a particular group of Muslims living in Antwerp (Belgium) with regard to dealing with medicine, health and illness, and specific treatmet decisions at the end of life. Very tentative conclusions were drawn with regard to the interplay between their religious views and their actual ethos. The ethical attitudes found among our interviewees were almost homogeneous. This is related to the homogeneity of their religious convictions. The overwhelming majority of our interviewees perceived God as almighty and all-knowing. They believed that God judges human beings' way of living, and that it has repercussions in the afterlife. Stressing their faith in God's sovereignty in the domain of life and death, these participants radically opposed every medical act which would contribute to a patient's death: voluntary euthanasia, assisted suicide, non-voluntary euthanasia, and mostly also withdrawal and withholding of treatment. Slight differences were found between Turks and Moroccans.

At the same time, we observed nevertheless that there might be openness for euthanasia among some Muslims. Saida (Moroccan) and Ayten (Turkish), who were both deeply religious, did not reject active termination of life. They toned down God's sovereignty with regard to death, and left room for human decision-making at the end of life. As such, our study showed that being a religious Muslim not automatically implies disapproval of active termination of life, and we discovered that specific religious beliefs, centring around God's characteristics, might exert an important influence with regard to views on specific ethical dilemmas in end-of-life care. Muslim participants who perceived God as an omnipotent, omniscient and judging God, were more likely to disapprove of every act which they perceived as active termination of life. Muslim participants (e.g. Saida) who reported that God is a protector of human beings, and that God does not decide

about suffering and illness, were more likely to *approve* active termination of life. At the same time, it must be stressed that we noticed that other factors (outside religion) might have a significant contribution. The influence of personal confrontation with illness will be further discussed in the epilogue of the doctoral dissertation.

Given the specificity of our research group, namely consisting of elderly (age ≥ 55), female Muslims of Moroccan and Turkish origin, having migrated to Belgium as spouses of 'guest workers' between the early sixties and eighties, and having always lived quite isolated from Belgian society, taking care of their household, being very poorly educated and often illiterate, and not or insufficiently speaking Dutch or French, we must be very prudent with a generalization of the findings, especially as far as the younger generations are concerned. At the same time, the small-scale, exploratory character of the study has to be kept in mind. And yet, we are convinced that our analysis can make valuable contributions. First, it points to the lacuna which exists in political, social and academic debates on the issue dealt with in this dissertation. In contemporary bioethical discussions about concrete hot topics, such as euthanasia, Islamic perspectives on the matter are not heard, despite the fact that Islam has grown into the second largest religion in Belgium. Second, the study may offer guidelines for health professionals in Belgium and other countries in the West, who may be frequently confronted with Muslim patients. The study points to the importance of profound knowledge about Islam and Islamic views on medicine, illness and treatment decisions at the end of life. It makes clear that in general, for religious Muslims, euthanasia is a taboo subject, that theological frameworks may be quite dominant in Muslim's everyday life, and that they often differ substantially from liberal right-to-die discourses which are quite popular in Western Europe. Simultaneously, the study warns for a stereotypic approach of Muslim patients. Thus, training of nurses and physicians should not only entail an introduction to Islam and possible sensibilities of Muslim patients, but it should also include acquiring the general skill of learning to appreciate a patient in his/her very specifics. This means that clinicians should not approach Muslim patients from a fixed idea of Islam they have in mind, but that they should pay attention to Muslim patients' particularities, with regard to their religiosity, and with regard to other factors (physical, psychological, social, ...) which shape their identity and which might have an influence when making health care decisions.

The epilogue of this doctoral dissertation offers comparative perspectives on the way of thinking of our Jewish and Muslim participants with regard to treatment decisions at the end of life. Given its limited empirical base, it offers very tentative insights into the way Jewish and Islamic beliefs and practices may influence the manner very specific moral dilemmas in end-of-life health care are dealt with.

EPILOGUE:

JEWISH & ISLAMIC END-OF-LIFE ETHICS

COMPARATIVE PERSPECTIVES

15 Introduction to Epilogue

After having examined Jewish (part 1) and Islamic (part 2) views on hot ethical topics in contemporary end-of-life care, and having particularly paid attention to a presentation and discussion of the findings of an exploratory qualitative empirical study conducted in the Orthodox Jewish and Moroccan and Turkish communities of Antwerp (Belgium), this epilogue aims to offer some tentative comparative perspectives. Specifically, it wants to describe the link we found between specific religious beliefs and the way ethical questions at the end of life are dealt with, and regarding this link, it wants to draw very tentative comparative conclusions with regard to two related (Abrahamic) religions (Judaism and Islam), living close to each other in the city of Antwerp (Belgium), at the same time being aware of huge differences (for instance with respect to socio-economic and educational level) between both.

In part 1 and part 2 we particularly focused, through codification of face-to-face interviews, on a reconstruction of the way of thinking of our research participants with regard to religion/world view and specific moral dilemmas in health care. (1) We inquired after religious beliefs and moral views of specific Jewish and Islamic populations in Antwerp (Belgium); (2) we confronted them with normative Jewish and Islamic standpoints, and (3) we tentatively explored the interplay between (the participants') religious views and moral attitudes on specific dilemmas in end-of-life care. Since the doctoral dissertation clusters articles which are suitable for individual publication in international scientific journals, each chapter also has its own specific topic and aim. For instance, in part 1, we included a review of Jewish end-of-life and bereavement rituals, in order to indicate how religious Jews cope with death. Additionally, we focussed on a review of Jewish views on euthanasia and withholding and withdrawing life-sustainment, and on retrieval of organs from brain-dead donors. In this way, we showed how Jewish ethical reasoning functions. The chapters which dealt with our empirical findings mainly focussed on a reconstruction of the Jewish and Muslim participants' way of thinking with regard to the research topic. Additionally, based on an analysis of the face-to-face interviews, tentative concepts were developed with regard to the religion-ethics interplay.

The epilogue of this doctoral dissertation aims to offer tentative comparative perspectives on the way of thinking of elderly Jewish and Moroccan and Turkish Muslim women (age $\geq$ 55) in Antwerp (Belgium) with regard to religion/world view and specific treatment decisions at the end of life. Keeping the small-scale, exploratory nature of the study in mind, we do not claim to have discovered substantial theories about the religion-ethics interplay. Only tentative concepts, which may form the basis for further (large-scale)

studies, result from our analysis. Of course, drawing cautious comparative conclusions with regard to the views of two Semitic religious communities (Judaism and Islam), which live next to each other in the city of Antwerp (Belgium), we keep their differences (for instance, with respect to socio-economic and educational level) in mind. This epilogue serves as general conclusion of the dissertation.

16 The Religion-Ethics Interplay in Jewish and Muslim Populations in Antwerp (Belgium): A Comparison

16.1 Introduction

This article explores the interplay between religion and ethics found in the attitudes of elderly Jewish and Muslim women in Antwerp (Belgium) towards end-of-life issues. The link between religion and ethics has often been taken for granted. Nevertheless, the question of *what constitutes this link* remains interesting. In this article we report on this aspect of our study. We explored the attitudes of elderly (age ≥55) Jewish and Muslim women in Antwerp (Belgium) on specific treatment decisions at the end of life (among others, withholding and withdrawing treatment, (non-)voluntary euthanasia and assisted suicide), making use of face-to-face interviews. Jews and Muslims in Belgium are under-researched populations. Especially with regard to end-of-life issues, public debate has been dominated by Christian and non-religious humanist voices (e.g., Schotsmans & Meulenbergs 2005; Distelmans 2005). As since the approval of the euthanasia act in 2002 (Belgisch Staatsblad 2002), the acceptability of euthanasia has frequently been discussed on both academic and social levels (mostly, from a Christian or non-religious humanist perspective), and given the fact that Jews and Muslims are important religious minorities in Belgium, we considered it meaningful to pay attention to their viewpoints on the matter. Of course, normative Jewish and Islamic perspectives on the topic have been published. Extensive Jewish discussions on ethical dilemmas in healthcare exist for quite a long time already (e.g., Jakobovits 1959; Freehof 1960; 1971; 1977; 1980; 1990; Bleich & Rosner 1979; Bleich 1981; 1993; Rosner 1986; Feinstein 1987; Sherwin 1990; 2000; Newman 1992; Jacob 1987; 1992; 1993; Jacob & Zemer 1995; Tendler 1996; Plaut & Washofsky 1997; Rosner 1997; Dorff & Newman 1995; Dorff 1998; Kaplan & Schwartz 1998; Mackler 2000; Rosner, Goldstein & Reichman 2003; Hurwitz, Picard & Steinberg 2006). Publications of normative Islamic viewpoints are rather recent and more limited (e.g., Rispler-Chaim 1993; Gatrad & Sheikh 2001; Brockopp 2003a; Atighetchi 2007; Brockopp & Eich 2008; Sachedina 2009).

To gain insight into the perspectives of a particular religion or world view on specific ethical dilemmas, these normative standpoints evidently are important sources. However, in order to get the whole picture, normative discourses must be distinguished from the actual ethos discovered among adherents of a particular religion. In studies of Jewish and Muslim perspectives on ethical dilemmas in healthcare this side of the picture has received less attention. Qualitative empirical studies with Jewish (Baeke, Wils &

Broeckaert 2011; Coleman, Koffman & Daniels 2007; Coleman-Brueckheimer, Spitzer & Koffman 2009; Leichtentritt & Rettig 1999) and Muslim (Van den Branden 2006; Van den Branden & Broeckaert 2008) populations regarding treatment decisions at the end of life are very scarce. And yet, qualitative empirical research creates the opportunity to further elucidate the religion-(end-of-life) ethics interplay. Given the specific nature of this kind of research, making use of in-depth face-to-face interviews, the question 'what constitutes the link between religion and ethics?' can be thoroughly explored. In order to do this, our empirical study took the multidimensional nature of religion into account (Glock & Stark 1966). Our research question was twofold: first, we investigated whether religion/world view influence the attitudes of elderly Muslim and Jewish women in Antwerp (Belgium) on ethical dilemmas at the end of life; and second, in case this influence would appear from our study, we would explore which facets of religion were (most) influential. The results section of the article describes our observations of the way of thinking of our research participants with regard to religion/world view and particular treatment decisions at the end of life. In the discussion section, we offer some tentative conclusions with regard to the interplay between both. Moreover, with respect to this link, comparative perspectives are offered regarding the Jewish and Muslim populations we interviewed. Although our participants belonged to very related Semitic religious traditions (either Judaism, either Islam), we take into account that - when comparing Jewish and Muslim views - certain variables, such as socio-economic and education level, were substantially different.

16.2 Method

This article applies qualitative analysis of interview data, collected among elderly (age ≥55) Jewish (n=23) and Muslim (n=30) women in Antwerp (Belgium) between June 2008 and June 2011. Jews and Muslims are important religious minorities in Belgium. In Antwerp, particularly, both Semitic religious traditions live close to each other. In Belgium, Jewish presence is centuries-old. Throughout history, the city of Antwerp became an important (Orthodox) Jewish center. Today, approximately 15.000-20.000 Jews live in Antwerp (in Belgium: 40.000-50.000) (Schmidt 1994; Abicht 2006; Brachfeld 2000; Saerens 2000; Vanden Daelen 2008). Muslim presence is rather recent. Migration from Morocco and Turkey started in the early 1960s when 'guest workers' were recruited to work in Belgian (mining) industry (Lesthaeghe 2000a; Reniers 2000; Surkyn & Reniers 1997). Ever since, Belgium has known a considerable growth in Muslim population (today approx. 600.000), especially in large urban areas (for instance in Antwerp: approx. 80.000) (Bousetta & Maréchal 2003; Pew Forum 2009; Hertogen 2010).

For the Jewish population, purposive sampling was done among elderly women, being a) Hasidic, b) non-Hasidic Orthodox, or c) secularized Orthodox. Secularized Orthodox Jews in Antwerp distinguish themselves from (non-)Hasidic Orthodox Jews in their interpretation of their Jewish identity. They understand their Jewishness in ethnic and cultural terms, instead of giving it a religious meaning. Since they do not follow (all) the prescriptions of Jewish law and they only rely on the (Orthodox) Jewish community for important rites of passage (e.g. circumcision, *bar mitzvah*, marriage, burial), they refuse to be perceived as Orthodox Jews. At the same time, being identified with progressive Judaism is for them a bridge too far. Their limited Jewish praxis is maintained out of habit or tradition, and because they consider it important to pass on Jewish tradition and culture to next generations. For the Muslim population, elderly Turkish and Moroccan women were recruited, who belonged to the first generation of Muslim migrants who settled in Belgium for economic reasons between the early 1960s and 1980s.

Due to the fact that the interviewer (first author) was female, for the interviews only Jewish and Muslim *women* were recruited. Because of the common separation between men and women in (Orthodox) Judaism and Islam, and the sensitive and confidential topics of the interviews, we assumed that a female interviewer would have difficulties with inspiring confidence in *male* interviewees. The reason why only *elderly* women (age $\geq$55) were interviewed, was related to the interview topic: it is more likely that elderly people are/will be (in the near future) confronted with ethical dilemmas in end-of-life care.

In order to uncover their attitudes on treatment decisions at the end of life, hypothetical cases were formulated which dealt with choices with regard to 1) curative or life-sustaining treatment, and 2) euthanasia and assisted suicide, on the basis of the conceptual framework of Broeckaert and the Flemish Palliative Care Federation (2006; Broeckaert 2008; 2009b). Another important part of the interview explored the religious identity of the participants. In order to do this, we relied on a six-dimensional religiosity measurement model which was inspired by sociologists Glock and Stark (1966). For each facet of religiosity, namely the ideological, intellectual, ritualistic, experiential, consequential, and social dimension, we phrased a number of questions. Apart from inquiring after religious identity and bio-ethical attitudes, the topic list of our interviews included questions on demographic aspects.

All women were interviewed individually, usually in their own house. As the Moroccan and Turkish respondents did not (sufficiently) master Dutch, the interviewer was assisted by two experienced interpreters (one fluent in Arabic and Berber, and one fluent in Turkish). All interviews with Jewish women were done in Dutch. The interviewees accepted to have the interview (which lasted on average 87 minutes) tape-recorded. Each interview was transcribed verbatim and the interview data were subjected

to profound analysis based on Grounded Theory methodology (Glaser & Strauss 1967; Strauss & Corbin 1998). Using software for qualitative data analysis, interview data were coded and interrelated. Codification allowed us to enter into and reconstruct the way of thinking of the research participants. Interviewing continued until theoretical saturation was reached. At a regular basis, observations were talked over with the research supervisors.

16.3 Findings

16.3.1 Sample characteristics

The interviewees' age varied between 55 and 75 years. From the Jewish participants, thirteen were born in Belgium. Twelve respondents (or their parents) lived in Belgium before the Second World War; the others migrated to Belgium afterward. The Muslim participants were born in Morocco or Turkey, and migrated to Belgium as spouses of 'guest workers' between the early 1960s and 1980s. In contrast to the Jewish interviewees, who were multilingual (mastering a.o. Dutch, French, English, Hebrew, Yiddish, Polish ...), the Muslim respondents only spoke Turkish, Arabic or Berber, and had no or only a very limited knowledge of Dutch. Some Moroccan respondents spoke a few words of French or Spanish. A considerable difference between the two samples was their degree of education: the Muslim interviewees were not or poorly educated and most (especially Moroccan participants) were illiterate. Most of them had always been housewives during their stay in Belgium and lived rather isolated from society. The Jewish participants on the other hand, had at least completed secondary education. Apart from caring for their family and doing the housekeeping, some of them were employed (for instance, as a teacher in (Jewish) schools, in (Jewish) shops, in office work or in social services). Most of them were actively engaged in the Jewish (Orthodox) community and/or Jewish charity. Especially secularized Orthodox women were also engaged outside the Jewish community. Participants were married (Jewish: 17; Muslim:16), divorced (Jewish: 3; Muslim: 5), or widow (Jewish: 3; Muslim: 9). Noticeably larger families were found among Orthodox Jewish (up to 10 children) and Muslim participants (up to 14 children) than among secularized Orthodox interviewees (up to 4 children).

16.3.2 Religious identity

In the 1960s sociologists Glock and Stark (1966) developed a multifaceted religiosity measurement model, distinguishing between five dimensions of religiosity: the ideological, intellectual, ritualistic, experiential and consequential dimension. Because of the

closeness and density of both Orthodox Jewish and Muslim (Moroccan and Turkish) communities, we assumed it was important to investigate the social dimension of religiosity, which concerns one's relationship with and integration in the broader religious community. With respect to Jews, Gutwirth (1970; 2004) published about the intense community life in the Orthodox Jewish – especially Hasidic – community of Antwerp. In other empirical studies among Muslims (Van den Branden 2006; Kemper 1996) this social dimension was added. In the pages that follow, we present these six dimensions of religiosity as found in our study.

16.3.2.1 Ideological dimension

> *The ideological dimension concerns the respondents' religious beliefs and the extent to which they concur with the set of beliefs of their religion.*

Most Jewish and Muslim respondents were (deeply) religious. In the Jewish sample, however, a distinction must be made between secularized Orthodox interviewees and (non-)Hasidic Orthodox participants. While most of the former were not or hesitantly religious, the latter were all intensely religious. Some secularized Orthodox Jewish interviewees renounced their faith in God because of the persecution of Jews throughout history. Ruth explained: "I cannot believe that there is a God who has created human beings who have so much evil in them". According to them, suffering and wars point to the non-existence of God. Leah was a secularized Orthodox woman who had faith in God. She saw God as a good God, who is powerless to do anything about the suffering in the world ("God does not want evil. I'm sure of that. I think sometimes God is also at a dead loss what to do"). Secularized Orthodox participants who said to be religious, did not endorse all prescriptions of Jewish law. Therefore, they refused to be considered as Orthodox Jews.

Hasidic as well as non-Hasidic Orthodox participants reported that for them God is omnipotent. God was seen as the creator and governor of the world. These participants argued that God is omnipresent and omniscient, and that everything is in God's hands. Elizabeth told: "One of God's names is Ha-Makon, the place. That means, wherever you are, everything, everything is God". The interviewees explained that God revealed the Torah (Jewish law) to humanity, and that God expects Jewish people to follow it. The interviewees understood God as the protector and helper of human beings, but at the same time they underscored that God puts human beings to the test (with misfortune, illness...) and judges their way of life, which must conform to God's guide (Torah) given to them. The Orthodox participants emphasized that it is essential for Orthodox Jews to follow the Torah, which was perceived as the divine manual for leading a good Orthodox Jewish life.

In this sense, Elizabeth described Judaism as a "to-do-religion". The interviewees underlined that in the end this 'orthopraxis' (correct practice) will be judged by God. It was expressed that in this life or in afterlife faithful behaviour will be rewarded.

The viewpoints of the Muslim interviewees with regard to God were very similar. In the same way, the Moroccan and Turkish respondents accentuated the almightiness of God. They saw God as the giver and taker of life, the creator and ruler of the world. Similarly to the Orthodox Jewish respondents, the Muslim participants were of the opinion that God decides about everything which happens on earth (including suffering, illness and death). The interviewees stressed that being a good Muslim implies following Islamic prescriptions, holding to the five pillars of Islam, and being able to distinguish *halal* (allowed) from *haram* (prohibited). As such, the Quran was understood as showing the correct Islamic way of life. Throughout the interviews, the centrality of performing good deeds was stressed. This was connected to the interviewees' faith in Allah's omnipresence and omniscience: the participants believed that Allah registers a person's behavior and deeds, and that after death they will be assessed. Accordingly a person will end up in paradise or in hell. "If you are a bad person in life, if you do not have faith in Allah, if you do not meet the Islamic obligations, you will be punished in the other world", Hülya (Turkish) said. Hence, the interviewees frequently underscored that life is a test or exam, during which Muslims can gather or lose points. Apart from being seen as the one who puts human beings to the test, Allah was also approached as their help and stay.

In the non-Hasidic Orthodox Jewish and Muslim sample, only a few voices which more or less deviated from the predominant view were found. Referring to the history of Jewish persecution and evil in the world, Esther and Norah expressed their doubt about God's omnipotence. "Sometimes he is a bit on a holiday", Norah said. Especially Esther had difficulties with having faith in a God who would control everything in this world, including illness and death. Saida was a Moroccan interviewee who uttered a similar hesitation. Both interviewees could not bear the idea that God would want human beings to suffer. As such, for them God was limited with regard to evil and suffering.

16.3.2.2 Intellectual dimension

> *The intellectual dimension is about the extent in which a religious person is informed about the basic tenets of his/her faith.*

Being member of the Orthodox Jewish community, (almost) all Jewish respondents had had a Jewish education. Yet, while the actual knowledge of the secularized Orthodox interviewees was mainly limited to Jewish history, culture and philosophy, the (non-

)Hasidic Orthodox participants seemed to be more informed about the Jewish religion. Almost all Hasidic and non-Hasidic Orthodox respondents said to read the Torah (principally on Sabbath) and recognized its great value, being the cornerstone of the Jewish religion. And yet, although some interviewees expressed their eagerness to deepen their knowledge of Torah, we also observed reluctance to it. During the interviews it was argued that profound study of religious books (*lernen*) is reserved for men. Moreover, especially rabbis were perceived as specialists regarding Jewish law (*halacha*), who can be addressed with complex questions: "The scholars, rabbis, they have learned so much that they have a better perspective and they can decide whether something is allowed or not" (Chanah - Hasidic). For the Orthodox Jewish interviewees, consulting a rabbi with regard to religious and everyday life seemed obvious. Moreover, it was emphasized that a rabbi's given advice on a particular case is absolutely binding. Devorah compared rabbis to traffic lights: "Lights tell us what to do: walk, do not walk... The rabbi, that's the light, what we are allowed to do and what we are not allowed to do. He shows the way, how we must live". The rabbi was considered to be the central reference when questions on Jewish law and on the correctness of a certain behaviour arise.

In the Moroccan and Turkish sample, the Quran was highlighted as being the essential source for living an Islamic way of life. Mehtap (Turkish) described it as "the way to Allah". And yet, only a minority of the interviewees (but considerably more Turks than Moroccans) were able to read and understand the Quran. Some reported that they followed classes to learn to read the Quran. Others said that they only try to remember those parts of the Quran which they need for prayer. In order to gather knowledge about Islam, some Moroccan participants said that they listen to audio-tapes or watch television programs about what is *halal* and *haram* in their religion. The Turkish respondents frequently made mention of Muslim authorities (*hoca*) who come on a regular basis from Turkey to Belgium. They told about a female *hoca* who teaches about Islam and the Prophet Mohammed's life in the local mosque, and who can be addressed for (religious) advice: "sometimes we do not know the answer, and then we ask the *hoca*. Islam is very delicate" (Ayten). Among the Moroccan interviewees, the religious expertise of imams was stressed. Some women mentioned that they always pick up something from the imam's sermon during the Friday prayer. It popped up during some interviews that it was unfitting for a woman to personally consult an imam.

16.3.2.3 Ritualistic dimension

> *The ritualistic dimension of religiosity concerns the extent to which adherents of a religion are involved in religious practice, which is expected from them.*

Among the (non-)Hasidic Orthodox interviewees the ritualistic dimension came forward in the importance of prayer, synagogue visit, celebrating Sabbath, festivals and rites of passage, and respecting Jewish dietary laws. In the interviews with the secularized Orthodox participants it appeared that they were very proud on being Jewish. Therefore they considered it important to pass this Jewish identity on to the next generations. That is why some considered it meaningful to celebrate certain Jewish festivals, to gather with family and friends on Sabbath, and to (partially) observe Jewish dietary laws. Dianne told that "at home everything is kosher out of habit and tradition". Often, it was also explained as a habit to pray on certain religious festivals or during synagogue ceremonies. Most secularized Orthodox interviewees reported to be not religious. Those few secularized Orthodox Jewish women who said they were, saw prayer as an essential part of their life, as they perceived God as their help and stay.

Among the (non-)Hasidic Orthodox Jewish participants, the ritualistic dimension proofed to be of huge importance. Eating kosher food was explained to be an essential prescription of Jewish law. All interviewees said to pray on a regular (usually, daily) basis. They explained that praying included uttering traditional Jewish prayers, as well as turning to God spontaneously during their daily activities. The interviewees remarked that praying expresses their connectedness to God, who permeates their whole life. They stressed that prayer asks ultimate concentration and profound devotion: "prayer cannot be rattled off, it must be thought over" (Danielle). Although Jewish women are exempt from synagogue visit, more than half of the (non-)Hasidic Orthodox interviewees reported to visit synagogue weekly (on Sabbath). Among them, the socializing element of synagogue visit came forward, but they underlined that the principal reason for attending a synagogue service is the special character of community prayer, which intensifies the experience of feeling connected to God. "In the synagogue you feel that you come closer", Nechama explained.

All (non-)Hasidic Orthodox respondents told they respect the Sabbath rest. Despite the intense preparations it requires, all women said to be craving for Sabbath, which gives peace, rest and renewed strength after a busy week. They explained that Sabbath gives the opportunity to stand still, physically and spiritually. For them, it is a holy day dedicated to prayer and hymns, a day on which they can distance themselves from secular worries and concentrate on God. "On Sabbath we can unite with God, come closer to God, improve ourselves in a certain way", Leyla noted. At the same time they mentioned the festive character of Sabbath: everybody is well-dressed, family and friends gather, and the most delicious food is served. All Orthodox interviewees experienced Sabbath as the highlight of the week. "Oh Sabbath, I would wish it for all people on earth. Sabbath is rest, Sabbath is

prayer, Sabbath is family life, Sabbath is delicious food, Sabbath is light, Sabbath is the most beautiful thing on earth", Tamar said.

In the interviews with the Muslim participants, four themes came forward with regard to the ritualistic dimension: prayer, mosque visit, Ramadan and pilgrimage (*Hajj*) to Mecca. All Turkish and Moroccan respondents said to pray (at least) five times a day, which is expected from pious Muslims, they added. Mimount (Moroccan) described praying as "doing Allah a favour". Similarly, Esra (Turkish) told she prays "because Allah asks it". In this sense, it popped up during the interviews that by fulfilling the Islamic commandment to pray, one scores good marks, which enhances a Muslim's chance of reaching paradise, the interviewees explained. The participants argued that praying asks energy and concentration, but that simultaneously it creates a good feeling. Rahma, for instance, said "when I've prayed, I feel calm, I have rest".

With regard to mosque visit, the interviewees stressed that it is not compulsory for Muslim women to visit mosque. Hence, most Turkish respondents reported to pray in mosque rarely if ever. In contrast, most Moroccan participants indicated to go to mosque weekly, on Friday. A lot of Moroccan and Turkish respondents who visit mosque regularly do this not only because of prayer, but also for attending a Quran class. The interviewees noted that during Ramadan, mosque visit is more frequent.

For the Moroccan and Turkish interviewees the month of Ramadan is very special. They considered it as a holy month, a month of fast, contemplation and peace. Ayten (of Turkish origin) pointed out that during Ramadan "you think of people who are poor and hungry". The interviewees stressed that, just like prayer, fasting during this month, is an essential Islamic obligation. Zohra (Moroccan) said: "Allah watches me. If I fast whole day, my efforts will be rewarded by Allah". Fatiha (Moroccan) underlined that Allah gives Muslims the strength and the patience to persevere in fasting.

When participants were asked about the pilgrimage to Mecca (*Hajj*), their reactions were highly emotional. A minority of the Moroccan and a majority of the Turkish interviewees reported to have done the *Hajj*. For them, it was a very special, beautiful and blissful experience. Dilek (Turkish) and Mariam (Moroccan) pointed to the purifying character of the *Hajj*: "it felt like all sins were cleansed", Dilek explained.

16.3.2.4 Experiential dimension

> *The experiential dimension concerns the experience of a transcendental, ultimate reality in daily life.*

The majority of the secularized Orthodox Jewish respondents expressed to have no faith in God or an ultimate reality. Some doubted the existence of God, but they did not experience any connection to God or a transcendental reality in daily life. Two secularized Orthodox respondents, who reported to be religious, did make mention of sometimes feeling God's presence or intervention. In contrast, all (non-)Hasidic Orthodox participants mentioned that they felt God's presence all the time during daily life. They told that especially in prayer, but also in daily activities, they felt connected to God: God stands next to human beings all the time. Chanah underscored God's omnipresence by referring to nature, which suddenly begins to sprout. The interviewees believed that every aspect of life is essentially permeated by God.

Very similarly, the Muslim participants were of the opinion that God's presence pervades everything. They explained that Allah is almighty, omnipresent and omniscient. Mariam (Moroccan) and Zehra (Turkish) referred to nature: flowers, rain, sun, "everything is from Allah", they explicated. Allah can even reverse the laws of nature, Mina (Moroccan) brought out. Throughout the interviews, luck, misfortune, health, illness, life and death were associated with Allah.

16.3.2.5 Consequential dimension

> *The consequential dimension of religiosity encompasses the impact of religion on a person's attitude and behaviour in everyday life: "the secular effects of religious belief, practice, experience and knowledge" (Glock & Stark 1966, p. 21).*

As was mentioned before, for the Orthodox participants their whole life is permeated by God. They reported that being an Orthodox Jew profoundly impacts on every aspect in life. The impact of their religion is noticeable in the way they live their life: where they enjoyed education, what they eat, when they work and rest, how they celebrate rites of passage, how they dress, etcetera. Their whole life is structured by religion.

The consequential dimension of religiosity particularly reveals itself in the importance attached to the regulations of Jewish law, according to which an Orthodox Jew is supposed to be living. The special role of rabbis came up frequently during the interviews: as specialists of Jewish law, they can give advice on the way a Jew is supposed to act in a certain situation.

In the secularized Orthodox Jewish sample, the consequential facet of religiosity appeared in another way. For instance, Leah's devotion inspired her to set up charity initiatives and to cope with her poor health. In the same way, Josephine's deep faith in God stimulated her to devote herself to a job in the social service sector.

Like for the (non-)Hasidic Orthodox interviewees, the Muslim participants' life revolves around Allah and the Quran. Especially prayer and Ramadan were considered to be essential aspects of being Muslim. In order to keep up to date about Islamic prescriptions, interviewees indicated to attend Quran classes, listen to audio-tapes, watch educative television programs, attend Friday prayer,... A lot of interviewees mentioned the importance of charity, helping other people, and the prohibition to steal, lie and gossip. At the same time, some interviewees recognized that it is not easy to be a good Muslim: "nobody can say 'I'm a perfect Muslim'; it can happen that you gossip about other people. Doing nothing wrong is simply impossible. Nobody on earth is perfect" (Mimount - Moroccan).

16.3.2.6 Social dimension

> *The social dimension concerns one's relationship with and integration in the broader religious community.*

As the worldwide Jewish community is famous for its cohesion, it was not surprising that the social dimension of religiosity was important for our respondents. The secularized Orthodox interviewees considered being Jewish and belonging to the Jewish people of paramount importance. "For me, being Jewish is a sense of belonging, a historical feeling, and a pride", Diane explained. Although the majority of them said that they were not religious, they stressed that they were member of the (Orthodox) Jewish community, which provides them with the necessary facilities for Jewish education, *bar mitzvah*, marriage, burial, etcetera. Most of these interviewees told that they were well integrated in the (Antwerp) Jewish community and that they had good contacts with Orthodox Jews.

The integration in the Jewish community of Antwerp and worldwide, was even more emphasized by the Hasidic and non-Hasidic Orthodox respondents. In Antwerp, the Jewish community provides necessary facilities to live an Orthodox Jewish life. There, the solidarity among Jews is very strong. Poor Jews can count on the community's assistance through voluntary charity initiatives. Apart from this local solidarity, the connectedness and solidarity felt among Jews worldwide was underlined. Sarah said: "we feel that we are one, we will sympathize when something happens, we believe that we are all bound together". It was told that Jews are considered to be one big family. This strong integration in the Jewish community also brings with it mechanisms of social control. Being surrounded by fellow Orthodox Jews – by living in a Jewish neighbourhood – urges one to preserve and strengthen one's Jewish identity.

A lot of Muslim interviewees indicated that they have been living a rather isolated life since they migrated to Belgium. While their husbands went to work, they were responsible for the household. A lot of women told that it is only now, with growing older, that they have more time to spend time with peers and to attend Quran classes. Özlem (Turkish) mentioned to be member of a Turkish non-profit organization which regularly organizes a reading group. Books with regard to Islam are read (by the chairwoman), explained and discussed: "we read a book and talk about what we have read, with regard to faith. Twenty women together talk, read and eat". Most Moroccan and Turkish interviewees indicated that mosque is an important meetingplace. Turkish respondents regularly referred to contacts with a (female) Turkish Muslim authority (*hoca*). Most interviewees lived in a neighbourhood with a lot of Muslim residents, which increases social control.

16.3.3 Attitudes towards ethical dilemmas in end-of-life care

Before exploring the link between religion and ethics as found in our study in the discussion section of this article, we present the attitudes of our participants toward concrete ethical dilemmas in end-of-life care.

16.3.3.1 Curative or life-sustaining treatment

Regarding choices with respect to curative or life-sustaining treatment, the interviewees were asked to react on three hypothetical cases. Two cases dealt with non-treatment decisions ("withdrawing or withholding a curative or life-sustaining treatment, because in the given situation this treatment is deemed to be no longer meaningful or effective"). One case related to refusal of treatment ("withdrawing or withholding a curative or life-sustaining treatment, because the patient refuses this treatment") (Broeckaert & FPCF 2006).

Secularized Orthodox Jewish interviewees strongly underscored the value of human autonomy and vehemently opposed initiating or continuing treatment which they deemed futile. With regard to withholding treatment Leah said therapy can be started "when life is feasible and realistic and it's bearable for the patient"; she added "when the patient says 'it's enough', well, then it's enough". Most of these respondents argued that, in careful consultation with physicians, close family members can make the decision to switch off medical devices which keep an unconscious patient artificially alive. The predominant view was that it is inhumane to be kept alive artificially. Only Joanna and Josephine disagreed with this: they saw it inhumane to stop life-support.

Most *(non-)Hasidic Orthodox* respondents underscored the importance of life preservation. Chiefly, it was argued that basically a Jew is obliged to choose for life. As such, the majority of the (non-)Hasidic Orthodox interviewees opposed withholding and withdrawing treatment. Arguments were mainly religious. Nechama (Hasidic) argued that "for a Jew every single day is important, every single hour, every single minute, every single moment he can do something which God asks to do". The respondents believed that, as life has been given by God, it must not be thrown away. Instead, nearly every effort must be made to extend life. Moreover, withholding, and especially withdrawal of treatment was considered to be a life-shortening act. As such, it was seen as an undesirable intervention with God's plan, who was perceived as the only author of life and death: "we never have the right to judge, who can live, who cannot. That's always heavenly work" (Nechama).

In the Hasidic as well as non-Hasidic Orthodox group it was frequently explained that in case of doubt, a rabbi's advice should be sought. They argued that given his expertise in Jewish law, a rabbi could pass a final judgment on the case: "I would do what is decided by the rabbi or explained by the law. Absolutely" (Sarah). In contrast to the Hasidic interviewees, some non-Hasidic Orthodox respondents stressed that the specific circumstances of a case should be taken into account. Esther and Norah were the only Orthodox interviewees who explicitly approved of withdrawal and refusal of futile treatment.

Among the *Muslim* participants it was frequently stressed that human beings must not give up hope upon confrontation with illness. Most participants were of the opinion that most people show a strong desire to live; as such they considered it very unlikely that a patient would refuse (curative) treatment. Predominantly, it was underscored that treatment must be initiated. The main argument was that taking care of one's body is a commandment of Allah. Yamina (Moroccan) said: "you have to do what Allah says: 'seek cure'". Reference was made to the famous saying of Prophet Mohammed: "For every disease, there is a cure", and it was underlined that a physician's task is to help people and to fight for life. Kezban (Turkish) emphasized that "doctors have taken an oath, they must fight for life". In this sense, withholding or withdrawing treatment would not be logical.

At the same time, the participants argued that seeking cure and relying on Allah should go together, since only Allah knows the outcome of the treatment: "A doctor must always give medication, he must treat you always, but maybe it helps, maybe not. If Allah wants, death comes, whether or not you take medication" (Yamina - Moroccan). Among our participants, refusal of therapy was chiefly seen as a sign of impatience and disobedience to Allah: "when she chooses not to be treated and she dies, she does not die as a Muslim", Aziza stated.

The primary argument against withdrawal of treatment was that this is a life-shortening act ("murder") which would constitute an intervention with Allah's will. The Muslim participants stressed their belief that only Allah decides about life and death: "in our religion, life has to be ended by Allah" (Mariam - Moroccan). While in the interviews physicians' erudition was frequently emphasized, at the same time they contrasted Allah's omniscience with doctors' limitations. As such, a doctor can *guess* that a certain treatment is futile, but in the end only Allah knows the outcome, they explained.

Hesitation with regard to the presented cases was more found among the Turks than among the Moroccans. With respect to initiating treatment some Turkish respondents said it is important to take case-specific circumstances into account. Hülya stated that treatment which is only meant to prolong life for some time, can be withheld in case there are "heavy side effects". As such, for some participants the unbearable suffering of a (cancer) patient outweighs the importance of treatment which may prolong life with a few weeks. In the same way, in the Turkish group openness was found for switching off medical devices when a patient is in an irreversible coma. Lale said that such a patient "is lying there like a dead person". Gamze agreed with this, stating "they are allowed to switch off the machines, because his life is over". There was also hesitation among some Moroccan participants: having been confronted with the suffering of her husband at the end of his life, Saida hesitated about the case. Farida (Moroccan) felt uncertain, because "only Allah knows" the outcome, she explained.

16.3.3.2 Euthanasia and assisted suicide

With regard to active termination of life, interviewees were asked to give their opinion about 1) voluntary euthanasia ("the intentional administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable by the patient, at this patient's request"); 2) assisted suicide ("intentionally assisting a person, at this person's request, to terminate his or her life"); and 3) non-voluntary euthanasia ("the intentional administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable, not at this patient's request") (Broeckaert & FPCF 2006).

In the interviews with the Jewish participants, a clear distinction could be made between the viewpoints of the secularized Orthodox interviewees on the one hand, and the opinions of the non-Hasidic and Hasidic Orthodox participants on the other hand. The latter made no considerable distinctions between these three treatment decisions. The general feeling toward the three hypothetical cases presented to them was discomfort and rejection. The predominant view was that active termination of life is absolutely not

allowed in Judaism. And yet, while *Hasidic* respondents absolutely repudiated every form of active termination of life, a few *non-Hasidic Orthodox* respondents were more moderate in their judgment. Elizabeth made clear that "the Jewish religion strongly emphasizes human beings' own responsibility". Tamar and Norah recognized that for some patients active termination of life could offer a way out of suffering, and hence, they deplored that Judaism prohibits euthanasia and assisted suicide. In the end, they repeated the predominant view that living a pious (Orthodox) Jewish life implied respecting and preserving human life.

In the argumentation of the (non-)Hasidic Orthodox women, references to God popped up frequently. It was expressed that bodies are God's – and not human beings' – property, that God is the only sovereign in the domain of life and death, and that (after death) God will judge human beings' actions. In the same way, with regard to non-voluntary euthanasia the predominant view was that humans do not have the right to pass judgment on human life.

Esther was the only Orthodox Jewish interviewee who very clearly approved of active termination of life. She had some reservations with regard to non-voluntary euthanasia, but with respect to voluntary euthanasia and assisted suicide she explicitly distanced herself from Jewish law. She explained that in case of unbearable suffering, a patient has the right to decide about his/her life. In contrast to the other (non-)Hasidic Orthodox Jewish respondents, she did not make mention of a God who is almighty with regard to illness, life and death.

Very similar to Esther, the *secularized Orthodox* interviewees dealt with the ethical dilemmas which were presented to them on a profane level. No reference was made to an ultimate reality or to Jewish religion. Instead, arguments in favor of voluntary euthanasia and assisted suicide were: the patient suffers unbearably, he/she lacks quality of life, his/her life is no longer meaningful, he/she has the right to self-determination with regard to his/her end-of-life. Stressing the importance of patient autonomy and warning for risks and dangers of abuse, the overwhelming majority of the secularized Orthodox respondents were unfavorably disposed toward non-voluntary euthanasia.

Among the (Moroccan and Turkish) *Muslim* interviewees, an absolute disapproval of active termination of life was observed. Often, respondents were scandalized about the hypothetical cases presented to them. Throughout the interviews the sinful character of acts which actively end life was emphasized. Voluntary and non-voluntary euthanasia were seen as murder, and assisted suicide was compared to suicide, acts which, according to the respondents, express impatience and ingratitude to Allah. Their argumentation was permeated with references to Allah: they brought out that only Allah is the author of life and death, that Allah has a meaningful plan with humanity which must be respected, that

Allah judges human beings' deeds, and that consequences will be felt after death. As such, they stressed, it is essentially important to patiently endure illness and suffering.

Only Saida (Moroccan) and Ayten (Turkish) uttered deviant stances. Both approved of voluntary euthanasia in case of a terminally ill patient with unbearable suffering. In the same way, Ayten (but Saida not) considered assisted suicide acceptable. Regarding non-voluntary euthanasia, only Ayten was favorably disposed towards it. In the interviews with Saida and Ayten, reference to religious arguments such as those above, were almost not found. Instead, they dealt with illness on a more profane level and they referred (at great length) to their husbands' agony at the end of their lives. Saida saw Allah more as the protector of human beings, than as the almighty ruler of health, illness, life and death.

16.4 Discussion

After having presented a reconstruction of the way of thinking of our participants with regard to religion/world view and ethical dilemmas in end-of-life care, in the discussion section we aim to investigate the religiosity-ethics interplay found in our study. Making use of a Grounded Theory methodology, our interview analysis and codification did not aim towards verification or falsification of hypotheses. Instead, Grounded Theory inductively allows the theory to emerge from the data. Taking the small-scale, exploratory nature of our empirical study into account, we did not develop a major theory with regard to the religion-ethics interplay (in general). Rather, codification of face-to-face interviews helped us to gain insight into and reconstruct the way of thinking of particular groups of Jews and Muslims living in Belgium, and to draw tentative conclusions with regard to the interplay between their religious identity and their particular ethos.

In general, empirical studies confirm that illness and health perceptions cannot be isolated from spiritual and religious beliefs (Coleman, Koffman & Daniels 1997; Bradshaw & Fitchett 2003; Ypinazar & Margolis 2006; Van den Branden & Broeckaert 2008; Harandy *et al.* 2010; Zeilani & Seymour 2010; Ahmad, Muhammad & Abdullah 2011). With respect to concrete ethical dilemmas in health care, previous studies show that the way of handling ethical questions is influenced by religion and world view. A considerable number of studies have confirmed that the stress on life-preservation is related to religiosity. For instance, Cohen *et al.* (2006b) observed that acceptance of euthanasia is related to a decreased level of religiosity. Other studies among the general public (e.g., Genuis, Genuis & Chang 1994; Achille & Ogloff 1997; MacDonald 1998; DeCesare 2000; Emanuel 2002; Ryynänen *et al.* 2002; Burdette, Hill & Moulton 2005; Rietjens *et al.* 2005; Rurup *et al.* 2005; Cohen *et al.* 2006b) and among care providers (e.g., Bachman *et al.* 1996; Portenoy *et al.* 1997; Grassi, Magnani & Ercolani 1999; Willems *et al.* 2000; Emanuel 2002; Ryynänen *et al.*

2002; Sprung *et al.* 2003; Miccinesi *et al.* 2005; Rurup *et al.* 2005; Sprung *et al.* 2007a; 2007b; Cohen *et al.* 2008; Gielen, Van den Branden & Broeckaert 2008; Broeckaert *et al.* 2009a; 2009b; Gielen, Van den Branden & Broeckaert 2009a; Inghelbrecht *et al.* 2009; Seale 2009; Smets *et al.* 2011) have endorsed this link between acceptance of active termination of life and (the intensity of) religious belief. Likewise, with respect to non-treatment decisions, empirical studies have confirmed that there is a link with religiosity (Sprung *et al.* 2007b; Zier *et al.* 2009). Brett and Jersild (2003) observed that insistence on aggressive medical treatment near the end of life is connected with religious convictions.

In our empirical study we made similar observations. In fact, our study provided new insights and a more thorough clarification of the religion-ethics interplay, due to its qualitative empirical methodology which allowed to delve deeper into the complexity of the topic, and given its substantial operationalisation of religion, relying on the multidimensional religiosity model of Glock and Stark (1966). In their review of surveys questioning the attitudes of nurses to euthanasia and/or assisted suicide, and assessing the influence of religion and world view on these attitudes, Gielen, Van den Branden and Broeckaert (2009b) found a very limited operationalisation of religion and world view. They noted that most frequently, respondents were (only) asked about their religious or ideological affiliation, and that studies did not take the complexity of religion as a multifaceted phenomenon into account. Moreover, the nature of surveys used in quantitative empirical studies is usually brief, in contrast to qualitative empirical studies which – making use of fieldwork and in-depth face-to-face interviews – give the opportunity to study a phenomenon in-depth. As said, due to the thorough operationalisation of religion used in our study, we could not only explore the religious and ideological identity of the interviewees in-depth, it also clarified our understanding of the interplay between their religion/world view and their perspectives on specific ethical dilemmas in end-of-life care.

As shown by previous studies (e.g., Rietjens *et al.* 2005; Cohen *et al.* 2008; Inghelbrecht *et al.* 2009; Smets *et al.* 2011), our research discovered that (the degree of) religiosity impacts on ethical attitudes. We found that practising Muslim and Jewish participants were predominantly opposed to every act which they conceived of active termination of life, and that in general non-religious secularized Orthodox Jewish respondents, on the other hand, were (more) tolerant toward euthanasia and assisted suicide and did not claim aggressive life-support. Similarly, DeKeyser Ganz and Musgrave (2006) observed that secular Israeli nurses tended to agree with physician assisted dying, while religious or very religious nurses were more likely to oppose it. A similar relationship between (the degree of) religiosity and the (non-)acceptance of active termination of life was distilled in other quantitative empirical studies with a Jewish sample (Musgrave,

Margalith & Goldsmidt 2001; Margalith, Musgrave & Goldschmidt 2003; Wenger & Carmel 2004). With respect to other treatment decisions, such as withdrawing life-sustaining treatment, a similar link was observed (Wenger & Carmel 2004). Studies among Jewish elderly have endorsed that there is an interplay between being (very) religious and the stress on the use of life-sustaining treatments (Carmel & Mutran 1997; Ejaz 2000). Studies with Muslim samples reveal comparable findings, namely that degree of religiosity negatively affects attitudes to practices which are perceived as active termination of life (Cavlak *et al.* 2007; Ahmed & Kheir 2006). In the studies of Cavlak *et al.* (2007), Ahmed *et al.* (2001), Ahmed and Kheir (2006) and Van den Branden (2006; Van den Branden & Broeckaert 2008) religious beliefs were mentioned amongst the reasons for opposing active termination of life. Similarly, with regard to the use of life-sustaining treatment, da Costa, Ghazal and Al Khusaiby (2002) noted that Muslim beliefs, such as the omnipotence of God, might play a role in being reluctant to withdrawal of life-support.

Likewise, among our study participants it was revealed that the religious beliefs a person has – the *ideological* dimension of religiosity – might impact on the way an ethical dilemma in end-of-life care is handled. Irrespective of religious affiliation, interviewees who believed that God is omnipotent, that God puts human beings to the test throughout life, and that God will evaluate a person's earthly deeds after life, were more likely to have a negative attitude to every act which they perceived as active termination of life. As such, not only (non-)voluntary euthanasia and assisted suicide were rejected, withdrawal (and often also withholding) of treatment, which was considered as contributing to a patient's death, were negatively perceived as well. The arguments they put forward when reacting on the cases presented to them contained a lot of references to God. For them God was omnipresent and omniscient. They were convinced that everything is in God's hands, that only God gives life and takes it away. As such, for them human beings do not have the authority to make the decision to end life. Moreover, these interviewees put earthly deeds in an eschatological perspective. Ending human life was considered to be a grave sin, which would have serious consequences in the hereafter. Patient endurance and reliance on God were seen as the correct way of coping with illness and suffering, which were perceived as a test from God, contributing to a person's well-being.

Our observation that religious beliefs – the *ideological* dimension of religiosity – influence the way ethical dilemma in end-of-life care are approached, was also confirmed among study participants who expressed their faith in a limited God who is powerless with regard to illness and suffering. They were more likely to approve of (voluntary) active termination of life. For instance, Esther, who was a non-Hasidic Orthodox Jew, and Saida, a Muslim from Moroccan origin, both were of the opinion that a patient has the right to take the decision to end his/her life. In contrast to Esther, who stipulated that a patient

always has the right to self-determination in matters of life and death, Saida restricted voluntary euthanasia to patients who are gravely ill, bedridden and not capable of autonomously ingesting medication orally. Both discussed active termination of life on a profane level, without (significant) references to God. In the same way, Leah, who was a secularized Orthodox woman with a deep faith in God, saw God first and foremost as the protector of human beings. All three could not imagine that God would want human beings to suffer. As such, for them, being deeply religious was not inconsistent with stressing human autonomy at the end of life.

Closely related to these findings, we infer that the *experiential* and *consequential* facets of religiosity too impact on opinions about end-of-life ethics. In our study, participants who felt that every aspect in life is permeated by God and who experience God as the one who stands next to human beings all the time and who registers all the actions of human beings, were much more likely to disapprove of active termination of life. For these participants, the impact of religion was felt in the importance which they attribute to following every prescription of the Jewish or Islamic religion. In the Jewish sample, these participants were more eager to consult a rabbi on how to behave correctly – namely: according to Jewish law – in a given situation.

The impact of the *experiential* and *consequential* dimension of religiosity on views on end-of-life ethics, was also observed among interviewees who felt God's presence chiefly as protective and consoling, and who admitted that they sometimes feel abandoned by God or even did not feel or believe in God's presence at all. They were much more likely to approve of active termination of life. In this group, the impact of religion was not (primarily) felt in following religious prescriptions, but rather in the importance attributed to doing good unto others.

In our findings, there are indications that the *social* dimension of religiosity too has an influence on the way people deal with ethical questions. The overwhelming majority of the Orthodox Jewish participants lived in the Jewish quarter of Antwerp, which is situated around the Central Railway Station and the city park. There, all facilities for living an Orthodox Jewish life are found: synagogues, kosher shops, Jewish schools, etcetera. Living very concentrated in this particular area of the city, social control is high. Similar mechanisms of social control can be found in Muslim communities in Antwerp. In the same way as the Jews, most Muslims in Antwerp live in neighbourhoods with a lot of fellow believers. As such, participants might have been reluctant to express viewpoints, for instance with regard to active termination of life, which might be in conflict with (normative) Orthodox Jewish, Hasidic or Islamic values. In the Orthodox Jewish sample this was also clear from the frequent references made to rabbinic authorities. Whenever hesitation arose with regard to a specific case, the interviewer was referred to rabbis, who

were considered to be *the* specialists in religious and ethical matters. Similarly, in their empirical study among strictly Orthodox breast cancer patients, Coleman-Brueckheimer, Spitzer and Koffman (2009) observed the involvement of rabbinic authorities in actual medical decision-making.

In the Muslim sample, the influence of the *social* dimension of religiosity was also noticeable in Saida's positive approach of voluntary euthanasia, which might have been related to her rather isolated position in the Moroccan community: her husband died, she was childless, and she had only scarce contacts with other Muslims. Similarly, in the Jewish sample, Esther's appreciation of voluntary euthanasia might have been related to her rejection of certain views and practices in Orthodox Judaism (she opposed Orthodox rabbis' interpretations of illness which she heard in synagogue, and the separation of men and women, for instance during parties of Orthodox Jews).

Apart from these different dimensions of religiosity which have a stronger or weaker influence on the way of dealing with a specific biomedical ethical challenge, our data showed that there might be a link between moral attitudes and personal experiences. The Orthodox Jewish and Muslim participants who uttered stances which deviated from the majority view, had been confronted with severe illness. Esther had survived breast cancer, and Saida and Ayten lost their husband after a lingering disease. Saida, in particular, referred to the unbearable suffering of her husband during his last moments of life. In contrast to most other Orthodox Jewish and Muslim participants, they did not have clear-cut answers which they perceived to be *the* normative Jewish or Islamic view. Van den Branden and Broeckaert (2008) noted a similar finding in their study among elderly Moroccan men in Antwerp. Driss, whose wife was gravely ill, was not able to give his opinion about the cases on active termination of life, while the other participants opposed it vehemently, referring to the normative Islamic view. Other empirical studies found that physicians (Smets *et al.* 2011) and medical students (Ahmed & Kheir 2006) who were more frequently involved in medical treatment of terminally ill patients, were more likely to support euthanasia. In the qualitative empirical study of Coleman, Koffman and Daniels (2007) on the other hand, strictly Orthodox Jewish breast cancer patients provided very clear-cut, normative Jewish answers to their illness. Very similar to the dominant opinion found among Jewish women in our study, they perceived illness as part of God's meaningful plan and stressed (apart from seeking cure) patient acceptance of it. Similarly, Malaysian Muslim women with breast cancer in the qualitative empirical study of Ahmad, Muhammad and Abdullah (2011), saw their illness as a test from Allah, to whom they should surrender.

Codification of our face-to-face interviews, which helped us to reconstruct our participants' way of thinking, helped us to draw some tentative conclusions with regard to

the interplay between religion and ethics found in our study. Our data analysis seems to make clear that that different aspects may have an important influence on the way a person deals with an ethical question: the ideological, consequential, experiential and social dimension of religiosity might have an impact, as well as personal experiences. In our study, it is remarkable that the overwhelming majority of the Orthodox Jewish and Muslim participants provide answers which conform to viewpoints found in literature which reflect normative Orthodox Jewish and Islamic perspectives. From our analysis of the ideological dimension of the participants' religiosity we can conclude that most of them adopt a very similar theological line of reasoning. With regard to active termination of life, as defined in our study, in Islam and religious Judaism a (nearly) univocal negative attitude is found (see e.g., Van den Branden & Broeckaert 2011a; Baeke, Wils, and Broeckaert 2011), which is framed theologically. In Islam, Brockopp (2003b) and Sachedina (2009) for instance, refer to teleological considerations, namely the Islamic belief in heaven and hell after death, and Sachedina (2009) points to the Islamic belief in God's almightiness: God alone is the creator of life and death. Van den Branden and Broeckaert (2011a) endorse that in English Sunni e-fatwas which discuss euthanasia and assisted suicide, frequent reference is made to the fixed, divinely decreed life span of humans. In normative Orthodox Jewish guidance on active termination of life too, the idea that God is the sole determiner of a person's life span, is a central theological thought (e.g., Bleich 1979a; 1979b; 1981). This is endorsed in other branches of Judaism (see e.g., Dorff 1998; 2000b; 2000c; CCAR 1997). As such, a cautious attitude toward quality of life judgments is predominant in religious Judaism (Schostak 1991; Glick 1999; Mackler 2003; Zohar 2006). Stress on human beings' duties (towards God and other humans), instead of emphasis on a person's rights, is characteristic for both normative Islamic and Jewish ethical reasoning (see e.g., Jotkowitz & Glick 2009b; Atighetchi 2007).

Our findings showed that in Islam and (Orthodox) Judaism diverse moral opinions may be found. This heterogeneity is characteristic for both religious traditions. When *muftis* or *poskim* (specialists in Islamic or Jewish law) consider an ethical query, the case is not only judged on the basis of general principles, rules and values found in the corpus of Islamic and Jewish law, but also taking case-specific circumstances into account. As such, the ethical reasoning found in both religious traditions has a casuistical nature. In Judaism, this "casuistic deontology" (Zoloth-Dorfman 1995) is characteristic for rabbinic *responsa*, which give ethical guidance to individual Jews in particular cases. The Reform Central Conference of American Rabbis, for instance, has been publishing collections of *responsa* ever since the mid-twentieth century (see ccarnet.org). On the Internet multiple "ask the rabbi" websites are available (see e.g., www.asktherabbi.org; www.aish.com). Similarly, Islam knows a tradition of issuing fatwas (legal opinions) on specific societal and ethical topics. On diverse websites (see e.g., www.islamonline.net; www.islam.tc/ask-imam/) fatwas dealing

with specific religious and (bio-)ethical queries are published (Van den Branden & Broeckaert 2010; 2011a; 2011b). Thus, in both religious traditions, similar ethical queries may yield different answers given the particular context of each case. As such, normative pronouncements leave space for the particularities of a case (Reinhart 2003; Brockopp 2003c). Brockopp notes that Islamic ethical guidance tries to respect a "balance between general rules and individual circumstances" (2008, p. 7). Similarly, Mackler (1995, pp. 177-193) and Jotkowitz (2010, pp. 38-55) describe Jewish ethical reasoning as a "reflective equilibrium approach" or back-and-forth reasoning between specific cases and general principles.

The case-oriented nature of both Islamic and Jewish ethical reasoning points to both traditions' flexibility and inner diversity. However, while there are different schools of thought in Judaism and Islam, normative guidance with regard to active termination of life seems very rigid and monolithic. Focussing on the ethos of a particular group of adherents of Judaism and Islam, our study showed that *in practice* voices of Jews and Muslims can be found which are more moderate and this not only in secularized groups like the secularized Orthodox. Our empirical study confirms that particular adherents of Judaism or Islam are shaped by different aspects, which may be important influential factors in their specific moral coping. While our findings suggest that personal experience with illness and suffering may yield viewpoints which are very different from normative Jewish and Islamic perspectives, further qualitative empirical research among Muslims and Jews, for instance in concrete palliative situations is needed to explore this in greater depth.

16.5 Conclusion

Current literature and reports of empirical studies endorse the interplay between religion and ethics. At the same time these studies are limited. Our exploratory qualitative empirical study corrects for this limitation by creating a thorough operationalisation of religiosity. As such, the influence of religiosity on the way one handles ethical dilemmas, such as euthanasia and assisted suicide, was addressed in its complexity. In sum, our study results indicate that different dimensions of religiosity might have a stronger or weaker influence. Most obvious was the important impact of the ideological dimension of religiosity. More particular, the image the interviewees had of God or an ultimate reality played an important role in the way the ethical dilemmas presented to them were handled. Moreover, in our analysis of the findings, we discovered that other dimensions of religiosity, namely the experiential, consequential and social dimension might have an influence. Additionally, from our findings we inferred that personal confrontation with illness might have an impact on approaching ethical dilemmas in end-of-life care, and that

it might yield viewpoints which are more or less different from what is perceived to be the normative Orthodox Jewish or Islamic view.

These conclusions are very tentatively drawn from an analysis of our face-to-face interviews among very particular Jewish and Muslim populations in Belgium. The study which was set up was very small-scale and exploratory in nature, and primarily aimed at entering into and reconstructing the way of thinking of under-researched religious minorities. Thus, future (large-scale) research is needed to further elucidate our observations. A situational qualitative empirical study could be set up in concrete palliative care settings. We are very prudent in generalizing the findings of our study, given the very particular sub-group of Jews and Muslims interviewed (participants were elderly people and female; a lot of them lived rather isolated from the world outside their own religious tradition and community; most Muslim participants were poorly educated and illiterate). Large-scale follow-up studies could investigate the impact of gender and age in greater depth. It could be (further) scrutinized whether male Jews and Muslims utter different perspectives on the topic. While our sub-groups of elderly Muslim and Orthodox Jewish women showed important similarities, it would be interesting to investigate whether this would be the case among younger generations of Orthodox Jews and Muslims (who are usually more integrated in the world outside their own religious community). Moreover, it could be investigated whether among Muslims in Belgium opinions similar to those put forward by the secularized Orthodox Jews are found.

Our study was limited by the smallness of the sample. Yet, interviewing continued until no new information was yielded through further data gathering. At that point, theoretical saturation was reached. Assistance from experienced interpreters was sought for the interviews with the Moroccan and Turkish women. We are aware of their possible influence on our findings, as studies show that interpreters are not neutral transmitters of a message (Freed 1988; Edwards 1998; Jentsch 1998; Kapborg & Berterö 2002; Liamputtong 2010). Moreover, despite the fact that anonymity and confidentiality were assured, participants might have been reluctant to express viewpoints which might not be tolerated in Islam or (Orthodox) Judaism.

APPENDIX:

TRANSCRIPTION AND CODIFICATION

OF FACE-TO-FACE INTERVIEWS

As mentioned in our general introduction, this appendix provides an illustration of the transcription and codification process of our face-to-face interviews. The table below provides examples of interview excerpts, and the codes which were extracted from them.

Interviewee	**Interview Excerpt**	**Open Coding**	**Axial Coding**
Leah	God has been my **saviour**. He has saved my child, He has saved me from death, maybe. (…) And I cannot bear the idea that they say that God has not done anything during the war. I think God could not do anything about the German army, about the mentality of Hitler. He **could not do anything** about it.	God protects God is powerless	Different images of God: ➢ protector ➢ doctor ➢ sovereign o omnipresent o almighty o ultimate creator o the greatest ➢ powerless
Elizabeth	One of God's names is Ha-Makon, the place. That means, wherever you are, everything, **everything is God**.	God is omnipresent	
Tzippa	I know that God **governs** the world and **everything happens according to His will.** (…) I know, if God does not want me to be cured, then I won't be.	God is almighty God is the sovereign	
Chanah	**Cure** comes from	God cures	

	God. The doctors are His assistants. That's the way we see it. Actually, the doctor was sent by God to help, but he does not know everything. **God knows more.**	God is omniscient	
Esra	**Everything is from Allah.** Being in the womb of your mother for nine months,… Illness too comes from Allah.	God is the creator of everything	
Zohra	Allah is the **greatest.** Allah is the professor. For everyone. Allah **gives** my ears, Allah gives my tongue, my food. **Everything** is from Allah.	God is the greatest God is the creator of everything	
Hülya	**Cure** comes from Allah. (…) **If Allah does not want it,** maybe a more serious illness will happen to me.	God cures God is almighty God is sovereign	

Interviewee	**Interview Excerpt**	**Open Coding**	**Axial Coding**
Rahma	We all die. And in the grave it happens. If you **behaved well,** you enter **paradise.** If you **behaved bad,** you go to the fire, to **hell.**	afterlife paradise hell good/bad acts	Eschatological views: ➢ afterlife: o Allah judges/rewards o paradise/heaven: ▪ good acts

Fatiha	If I feed people during Ramadan, I'll receive **good marks**. And if I'll die, **Allah will open His book** (…)	good marks Allah judges Allah rewards	▪ good marks o hell: ▪ bad acts o Messiah o body/soul o earthly life = preparation
Kezban	If we are a **good** human being in this life, then we **will see Allah** after death.	good behaviour Allah rewards	
Handan	If you **act well**, you'll enter **heaven**.	good behaviour heaven	
Chanah	Our life on earth is a **preparation** for the afterlife. If we **behaved well**, we'll have a good time in the hereafter. If not, you will face several difficulties.	this life = preparation for afterlife good behaviour	
Suzannah	We hope that if **Messiah** comes, the world will be delivered from evil.	Messiah	
Tamar	I really believe **life goes on** after death. And I believe the **Messiah** will come. Absolutely.	Afterlife Messiah	
Norah	I believe there is a **soul**, but I don't know what happens with it.	soul	

Interviewee	**Interview Excerpt**	**Open Coding**	**Axial Coding**
Ruth	Illness is an **imbalance** in	imbalance	Interpretations of illness

	the body which can be **caused by** a poor diet. It can be caused by making a wrong move or by the quality of air we breath.	profane cause	➢ cause: o profane (e.g. imbalance) o God ➢ divine purpose: o test o exhortation o purification (for afterlife) o not a punishment ➢ Answer to illness: o turn to Allah: ▪ patience ▪ gratefullness ▪ prayer o consult a physician: ▪ take medication
Tamar	Maybe there is, when **He [God] causes illness,** He wants us to **think** a bit, and to **live** a little bit **better.**	God's plan exhortation	
Miriam	We don't know. But the rabbis think that and we also think that this is a **test,** a test. Everyone is tested in his life. […] They say that good people maybe pay in this world for that little thing they have done wrong. And then they are **pure** in the other world. Maybe, we think, these are opinions. But not sure. But certainly it is not a punishment.	a test purification not a punishment	
Kezban	Illness **comes from Allah,** and cure as well.	Allah's plan	
Ayten	Allah puts us to the **test,** whether in illness you stay **patient** and **grateful** to Allah, and	Allah's test patience gratefullness prayer	

	whehter you pray to Allah. It's Allah's testing.		
Fatiha	Someone who behaved bad, someone who suffers a lot of pain, his means that his sins diminish. If Allah wants him to suffer, this means that he is a bit **purified** from sin. Af if he dies, he will go to paradise.	purification	
Hülya	Cure comes **from Allah**. When I'm ill, for instance bronchitis, I must **go to the doctor**. And I must **take my antibiotics** and I will be cured. But **if Allah does not want it**, maybe a more serious illness will happen to me.	Allah decides consult a physician take medication	

SUMMARY

In contemporary hospital settings in Belgium answering spiritual and ritual needs of patients, for instance by providing them spiritual support and facilities for prayer, has become an integral dimension of care. In recent pleads for the provision of religion- and culture-sensitive care, there is an increasing awareness that the way people deal with illness and health care is in an important way influenced by religion or world view. This dissertation aims to elaborate on the idea that the importance of religion and world view in health care extends beyond merely spiritual care.

The ways in which the ethical dimensions related to health care decisions are handled differ widely. It is quite plausible that religious people might not deal with ethical dilemmas in medicine in the same way as, for instance, non-religious humanists do. Although the link between religion and ethics has often been taken for granted, the question of what precisely constitutes differences in handling ethical dilemmas remains interesting. Differences might relate to people's world view: ideas about ultimate reality, humankind and life might influence opinions on what ought to be, including what to decide in the face of an ethical dilemma.

In Belgium, in the build-up to the euthanasia law, and ever since its enactment in 2002, debates revolved around people's right to die, particularly among scholars, ethicists and policy makers having either a Christian, either a non-religious humanist background. Until today, in societal, political and academic conversations on the topic, voices of Jews and Muslims - the two largest religious minority groups in Belgium - are absent, while, at the same time, given the multicoloured character of present-day society, there is an urgent need for culture- and religion-sensitive care. This doctoral dissertation aimed to meet this lacuna by studying (Flemish) Jewish and Muslim perspectives on ethical dilemmas in end-of-life care. Therefore, an exploratory qualitative empirical study was set up in the (Orthodox) Jewish and Muslim communities in Antwerp (Belgium). This non-normative descriptive qualitative empirical study focused on two central research questions: (1) what are the attitudes of elderly Jewish and Muslim women (age $\geq$ 55) living in Antwerp (Belgium) toward ethical dilemmas which may occur in contemporary end-of-life health care?; (2) to what extent does the participants' ethos correspond with or deviate from Jewish and Muslim standpoints found in normative literature? Additionally, the study explored (3) whether there is a link between specific religious beliefs and the way ethical questions at the end of life are dealt with, and what precisely constitutes this link. Moreover, (4) regarding this link, we aimed to draw very tentative comparative conclusions with regard to two related (Abrahamic) religions (Judaism and Islam), living close to each

other in the city of Antwerp (Belgium), at the same time being aware of huge differences (for instance with respect to socio-economic and education level) between both.

A Grounded Theory methodology, which makes use of an inductive method, was applied to analyse the interview data. Keeping the exploratory nature of the empirical study in mind, we did not develop substantial theories, for instance with regard to the religion-ethics link in general. Our primary purpose was to enter into and reconstruct our participants way of thinking with regard to religion, illness, medicine and specific treatment decisions at the end of life, via a codification of the interview data.

In the first part of the doctoral dissertation we elaborate on Jewish perspectives on the topic under study, as Jews are an important and long-standing population in Belgium. The first chapters of this part were meant to gain insight into normative Jewish perspectives on death and specific ethical dilemmas in health care. In the first chapter after the introduction to the first part, we analyze Jewish perceptions of life and death and Jewish end-of-life rituals. In this chapter, we argue that Judaism strongly rejects the rule of death, despite the fact that the Jewish tradition takes human contingency seriously. We discover that in Judaism, even when death comes knocking, stress on life prevails. The chapter focuses on three central elements which drop a hint in that direction: (1) discontinuity (life and death appear as two strictly separated spheres), (2) continuity (stress on the existence of life after death), and (3) community (which plays an essential life-giving role).

In the subsequent chapters, the focus is narrowed down to very concrete ethical dilemmas and Jewish views on it. First, we discuss the (American) Jewish debate on the acceptability of using organs retrieved from brain-dead patients. In religious Jewish circles, it is disputed whether extraction of these organs should be considered murderous. This review of North American religious Jewish perspectives on the issue of retrieval of organs from a heart-beating brain-dead donor reveals that two approaches are dominant. While liberal (Conservative as well as Reform) American rabbis appear to agree with the acceptability of organ transplantation, no unanimity is found among prominent Orthodox American rabbis. By examining this much-debated ethical query, the chapter aims to reveal the specificity of Jewish ethical reasoning, its text-centeredness and heterogeneous character.

Second, Jewish perspectives on euthanasia are explored, on the basis of a review of publications of prominent rabbis who have extensively published on Jewish biomedical ethics. In the chapter, we look into Orthodox, Conservative and Reform opinions on euthanasia, and we discover an inner-Jewish as well as intra-branch diversity. In our review, we find no advocates of euthanasia in the Orthodox movement. In the Conservative as well as Reform movement, we record a diversity of opinion. Without neglecting this inner-

Jewish heterogeneity, we stress, however, that pro-euthanasia opinions are exceptional voices, even within the Conservative and Reform branches of Judaism. Again, apart from Judaism's essential diversity, the debate on euthanasia discloses that ethical reasoning in Judaism predominantly presupposes reference to the Jewish textual tradition.

Third, we probe the position of prominent Orthodox Jewish authorities with regard to withholding and withdrawing life-sustaining treatment, and we confront them briefly with Conservative and Reform perspectives on the topic. This chapter centres around the Jewish emphasis on the preservation of life, and shows that Jewish views on the permissibility of withholding/withdrawing life-sustaining treatment are again rather diversified. Divergent opinions are found in all Jewish movements.

The chapters which reviewed normative Jewish perspectives on organ donation, euthanasia and withholding/withdrawing life-sustaining treatment functioned as a first necessary acquaintance with the specificities of Jewish ethical reasoning. The chapters show that Jewish medical ethics is casuistic and gives evidence of a 'heterogeneous specificity': rabbis, who deal with present-day ethical queries in end-of-life care, draw on a common arsenal of values, principles and texts, which are not shared by all at all times, and interpreted or used in a similar way.

The three subsequent chapters focussed on an examination of the actual ethos of a particular group of Jews living in Antwerp (Belgium). From June 2008 until January 2009, 23 face-to-face interviews were conducted with a purposive sample of elderly (age $\geq$ 60) Hasidic, non-Hasidic Orthodox and secularized Orthodox Jewish women in Antwerp. Given the female sex of the researcher and the strict separation between men and women in traditional Judaism, only women were included in the study. In the dissertation, we subsequently outline the perceptions of our research participants with regard to a) illness and medicine, b) active termination of life, and c) withholding and withdrawing life-sustaining treatment. In these chapters, we developed some tentative concepts with regard to the link between Jewish beliefs and ethical attitudes. Among Orthodox Jewish participants it was predominantly found that every action which was perceived as active termination of life was rejected, because of their emphasis on the sanctity of human life. Secularized Orthodox Jews were more likely to stress quality of human life and human autonomy, and to accept active termination of life.

Further, our empirical study showed that the interplay between religion and ethics found in our sample is very complex. We found religious women who approved of euthanasia, despite their faith in God. We discovered that not so much being Jewish, but ***what interviewees believed*** and their ***image of God***, had an important impact on their moral attitudes. In our empirical findings we, first, discovered that interviewees who did not have faith in God or an ultimate reality, were more likely to underline a person's absolute right

of self-determination with regard to life and death. Life, death, illness and health were not associated with God or a transcendental reality, but were interpreted on a purely profane level and seen as mere coincidence. These interviewees were very tolerant toward active termination of life and withholding and withdrawing of life-sustaining treatment. Second, participants who had faith in an almighty, omniscient God, were more likely to put human beings' fate in God's hands. They believed that God created the world, and that He governs human beings' life and death. Interpreting life, health, illness and death on a transcendental level, they were more likely to oppose human intervention in the realm of life and death. As such, they took a very negative stance toward every act which they perceived to be active termination of life: euthanasia, assisted suicide, and often also withholding and withdrawal of treatment. Third, irrespective of being (non-)Hasidic Orthodox or secularized Orthodox, interviewees who had faith in God, but who refused to believe in God's almighty power with regard to life, death, illness and health, were more likely to stress human beings' right to decide about the end of their life. God would not want human beings to suffer, they argued, thus leaves room for ending their lives in a situation of unbearable suffering.

In comparison to the centuries-old presence of Judaism in Belgium, the emergence of Islam in the country is rather recent. Yet, ever since Muslim migration to Belgium started in the late 1950s-early 1960s, the Muslim population continues growing. Considering this, and given the fact that first generation migrants of Moroccan and Turkish origin grow old today, and hence might have increasing medical needs, we considered it important to investigate Islamic views on ethical dilemmas in end-of-life health care. More specifically, the second part of this dissertation constitutes of a presentation and discussion of the data obtained from our exploratory qualitative empirical study conducted in the Turkish and Moroccan Muslim communities in Antwerp (Belgium). Given the research expertise of the Interdisciplinary Centre for the Study of Religion and World View (KU Leuven) - normative Islamic views on ethical dilemmas in end-of-life care were already extensively investigated in the past - we did not assume it useful to give in our text an overview of Islamic end-of-life ethics in general. Therefore, the second part focuses on reconstructing the way of thinking of a particular group of Muslims living in Antwerp (Belgium) with regard to religion, medicine, illness, and specific treatment decisions at the end of life. From June 2009 until January 2011 face-to-face interviews were done with 30 elderly (age $\geq$ 55) first generation Muslim women of Moroccan (15) and Turkish (15) origin, with the assistance of two experienced interpreters, fluently speaking Turkish, Moroccan and Berber. Given the segregation of the sexes in Islam, as a *female* researcher we only recruited Muslim *women* to participate in the study. In three subsequent chapters in the second part of the dissertation, we discuss the views of the interviewees on a) medicine, illness and suffering, b) active termination of life, and c) non-treatment decisions. In the

discussion section of the chapters, the views are confronted with normative Islamic standpoints.

To sum up, the religious views and ethical attitudes found among our interviewees were almost homogeneous. This is related to the homogeneity of their religious convictions. The overwhelming majority of our interviewees perceived God as almighty and all-knowing. They believed that God judges human beings' way of living, and that it has repercussions in the afterlife. Stressing their faith in God's sovereignty in the domain of life and death, these participants radically opposed every medical act which would contribute to a patient's death: voluntary euthanasia, assisted suicide, non-voluntary euthanasia, and mostly also withdrawal and withholding of treatment. Slight differences were found between Turks and Moroccans.

At the same time, we observed nevertheless that there might be openness for euthanasia among some Muslims. One Turkish and one Moroccan interviewee, who were both deeply religious, did not reject active termination of life. They toned down God's sovereignty with regard to death, and left room for human decision-making at the end of life. They reported that God is a protector of human beings, and that God does not decide about illness and suffering. As such, our study suggests that being a religious Muslim not automatically implies disapproval of active termination of life. We also noticed that personal confrontation with illness might have a significant influence. Anyway, we discovered that specific religious beliefs, centring around God's characteristics, might exert an important influence with regard to views on specific ethical dilemmas in end-of-life care. The overwhelming majority of our Muslim interviewees expressed a strong disapproval of every act which was perceived as active termination of life. We concluded that this attitude was related to their image of God: omnipotent, omniscient and judging.

The epilogue of the dissertation aims to offer some preliminary comparative perspectives on the way of thinking of our Jewish and Muslim participants with regard to treatment decisions at the end of life. It offers very tentative insights into the way Jewish and Islamic beliefs and practices may influence the manner very specific moral dilemmas in end-of-life health care are dealt with. Drawing very tentative conclusions, we take into account that - when comparing Jewish and Muslim views - certain variables, such as socio-economic and educational level, were substantially different. Specifically, this epilogue takes the multidimensional nature of religion into account, and explores which facets of religion were most influential in the religion-ethics interplay we discovered in our empirical studies. As such, in this epilogue, the influence of our participants' religiosity on the way they handle ethical dilemmas is addressed in its complexity. In sum, our study results indicate that different dimensions of religiosity have a stronger or weaker influence. Most obvious is the impact of the ideological dimension of religiosity (a person's image of and beliefs

about God or ultimate reality). Irrespective of religious affiliation, interviewees who believed that God is omnipotent, that God puts human beings to the test throughout life, and that God will evaluate a person's earthly deeds after life, were more likely to have a negative attitude to every act which they perceived as active termination of life. As such, not only (non-)voluntary euthanasia and assisted suicide were rejected, withdrawal (and often also withholding) of treatment, which was considered as contributing to a patient's death, was negatively perceived as well. Additionally, the epilogue shows that other factors, such as personal confrontation with illness, might have an impact on approaching ethical dilemmas in end-of-life care, and that it might yield viewpoints which are more or less different from what is perceived to be the normative Orthodox Jewish or Islamic view.

Annexed theses

1. In our study, Orthodox Jews predominantly oppose every action which is perceived as active termination of life, stressing the sanctity of human life, while secularized Orthodox Jews are more likely to stress quality of human life and human autonomy, and to accept active termination of life.

2. Elderly first generation Muslim women in Antwerp (Belgium) expose almost homogeneous religious views and ethical attitudes: stressing their faith in God's sovereignty in the domain of life and death, they radically oppose every medical act which would contribute to a patient's death.

3. Jewish and Muslim women in Antwerp (Belgium) who have faith in an omnipotent, life-giving, judging God, are less likely to approve treatment decisions to which they attribute a death-hastening effect.

4. When life, death and illness are interpreted on a purely profane level, one is more likely to underline a person's right of self-determination with regard to life and death, and to be more tolerant toward active termination of life, and withholding and withdrawing life-sustaining treatment.

5. Personal confrontation with illness may have an impact on the way ethical dilemmas in end-of-life health care, for instance active termination of life, are approached; they may yield viewpoints which are more or less different from what is perceived to be the normative Orthodox Jewish or Islamic view.

6. Islamic and Jewish ethical reasoning are characterised by a case-oriented nature, which allows for flexibility and diversity in both traditions.

7. The finding that similar religious beliefs have a strong influence on the attitudes of Jewish and Muslim participants with regard to hot ethical topics in end-of-life care offers interesting opportunities for interreligious dialogue.

8. Given the increasingly multicultural and multi-religious outlook of contemporary health care, it is a huge but indispensible challenge to take patients' (cultural) background and religious convictions, which may impact considerably on medical decision making, into account.

9. The increasing plurality of religions and cultures in present-day Western society urges caregivers to acknowledge that treatment decisions are not value-neutral, and therefore to pay considerable attention to development of contextual sensitivity, clarification of differences between their own value-system and that of patients, and effective communication.

10. Heterogeneity is characteristic for both Judaism and Islam; therefore it is not appropriate to approach Jewish and Muslim patients in a simplistic, stereotypic and non-nuanced way.

SAMENVATTING

Het beantwoorden van spirituele en rituele noden van patiënten is in de hedendaagse ziekenhuissetting in België een integrale dimensie van zorg: pastors verschaffen spirituele steun en gebedsfaciliteiten worden verzorgd. In recente pleidooien voor het verschaffen van religie- en cultuurgevoelige zorg is er een groeiende bewustwording merkbaar van het feit dat de manier waarop mensen omgaan met ziekte en gezondheidszorg in belangrijke mate wordt beïnvloed door hun levensbeschouwing. Dit proefschrift wil verder ingaan op het idee dat het belang van religie en levensbeschouwing in de gezondheidszorg verder reikt dan het verschaffen van spirituele zorg.

De manier waarop met ethische uitdagingen verbonden aan beslissingen in de gezondheidszorg wordt omgegaan, kan grondig verschillen. Het is heel waarschijnlijk dat mensen die zichzelf religieus noemen op een andere manier omgaan met ethische dilemma's in de geneeskunde dan, bijvoorbeeld, vrijzinnigen. Hoewel de link tussen religie en ethiek vaak als vanzelfsprekend werd beschouwd, blijft het interessant de precieze verschillen in het omgaan met ethische dilemma's na te gaan. Verschillen kunnen gerelateerd zijn aan levensbeschouwing: bepaalde opvattingen over het leven, over de mens, en over (het bestaan van) een transcendente werkelijkheid kunnen opinies, bijvoorbeeld met betrekking tot prangende ethische kwesties, beïnvloeden.

In de aanloop naar de Belgische euthanasiewet die in 2002 van kracht ging, ontsponnen zich talrijke debatten over het recht op sterven. Deze debatten werden vooral gevoerd tussen academici, ethici en beleidsmakers met een christelijke of vrijzinnige achtergrond. Tot op heden blijven de stemmen van joden en moslims - de twee grootste religieuze minderheidsgroepen in België - afwezig in maatschappelijke, politieke en academische debatten over het onderwerp. Dat terwijl er, gezien het veelkleurig karakter van de hedendaagse samenleving, een dringende nood is aan het verlenen van religie- en cultuurgevoelige zorg. Door het bestuderen van (Vlaamse) joodse en islamitische perspectieven op ethische dilemma's in de gezondheidszorg, heeft dit proefschrift tot doel deze leemte in te vullen. Een verkennend kwalitatief empirisch onderzoek werd opgezet in de (Orthodox) joodse en islamitische gemeenschappen in Antwerpen (België). Deze niet-normatieve, beschrijvende, kwalitatief empirische studie focuste op twee centrale onderzoeksvragen: (1) wat zijn de attitudes van oudere joodse vrouwen en moslima's ($\geq$ 55 jaar) die in Antwerpen (België) wonen ten aanzien van ethische dilemma's die kunnen opduiken in de hedendaagse zorg aan het levenseinde?; (2) in welke mate correspondeert het ethos van de deelnemers met of wijkt deze af van joodse en islamitische standpunten die we terugvinden in normatieve literatuur? Daarnaast had de studie tot doel (3) de link tussen specifieke religieuze overtuigingen en de manier waarop ethische vragen aan het

levenseinde benaderd worden, te onderzoeken. Bovendien (4) poogden we met betrekking tot deze link tentatieve comparatieve conclusies te formuleren over twee sterk verwante (Abrahamitische) religies (jodendom en islam), die in de stad Antwerpen (België) naast elkaar leven. Uiteraard waren we ons tezelfdertijd sterk bewust van belangrijke verschillen (bijvoorbeeld met betrekking tot socio-economisch niveau en scholingsgraad) tussen beide religies.

Om de interviewdata te analyseren maakten we gebruik van een (inductieve) Grounded Theory methodologie. Gezien het verkennend karakter van onze empirische studie, hadden we geenszins tot doel overkoepelende theorieën, bijvoorbeeld met betrekking tot een algemeen verband tussen religie en ethiek te formuleren. Als voornaamste onderzoeksdoel stelden wij het binnentreden in en reconstrueren van de denkwereld van onze respondenten met betrekking tot religie, ziekte, geneeskunde en specifieke medische beslissingen aan het levenseinde, via het coderen van interviewdata.

In het eerste deel van het proefschrift gaan we dieper in op joodse perspectieven omtrent het studietopic. De eerste hoofdstukken van dit deel beogen het verwerven van inzicht in normatieve joodse visies op de dood in het algemeen, en op specifieke ethische dilemma's in de gezondheidszorg. In het eerste hoofdstuk na de inleiding tot deel 1, analyseren we joodse visies op leven en dood en joodse rituelen aan het levenseinde. In dit hoofdstuk betogen wij dat het jodendom zich weigert neer te leggen bij de dood, ondanks het feit dat de joodse traditie de menselijke contingentie uiterst ernstig neemt. We ontdekken dat in het jodendom de nadruk op het leven primeert. Het hoofdstuk focust op drie centrale elementen die in die richting wijzen: (1) discontinuïteit (leven en dood zijn twee strikt gescheiden sferen), (2) continuïteit (nadruk op een leven na de dood), en (3) gemeenschap (die een essentiële levengevende rol speelt).

In de volgende hoofdstukken spitsen we ons toe op joodse visies op concrete ethische dilemma's. Ten eerste bekijken we het (Amerikaanse) joodse debat met betrekking tot het gebruik van organen van hersendode donoren. In religieuze joodse kringen wordt bediscussieerd of het verwijderen van deze organen moord impliceert. Deze review van Noord-Amerikaanse religieuze joodse visies op het verwijderen van organen bij hersendode donoren toont twee dominante benaderingen. Terwijl liberale (Conservative en Reform) Amerikaanse rabbijnen het eens zijn over de aanvaardbaarheid van (deze) orgaantransplantaties, vinden we geen unaniem oordeel bij prominente Orthodoxe Amerikaanse rabbijnen. Door stil te staan bij dit hete ethische hangijzer, wil dit hoofdstuk de specificiteit van het joodse ethisch redeneren aantonen. Daarbij valt vooral op dat (traditionele) teksten een centrale rol spelen, en dat de joodse ethiek sterk heterogeen is.

Ten tweede verkennen we in dit proefschrift joodse perspectieven op euthanasie. Hierbij baseren we ons op een review van publicaties van prominente rabbijnen die

uitgebreid gepubliceerd hebben met betrekking tot joodse biomedische ethiek. In dit hoofdstuk onderzoeken we Orthodoxe, Conservative en Reform opinies met betrekking tot euthanasie, en ontdekken we een intra-joodse diversiteit, die ook terug te vinden is in de diverse joodse stromingen. In onze review vinden we geen Orthodox joodse voorstanders terug van euthanasie. In de Conservative en Reform beweging, daarentegen, ontdekken we uiteenlopende visies. Zonder deze intra-joodse heterogeniteit te ontkennen, benadrukken we wel dat pro-euthanasie opinies slechts uitzonderlijke stemmen zijn, zelfs in de Conservative en Reform stromingen van het jodendom. Opnieuw ontvouwt dit hoofdstuk ook de eigenheid van het joodse ethische redeneren: de referentie naar een joodse tekstuele traditie, en de essentiële joodse diversiteit.

Ten derde belichten we in dit proefschrift de positie van prominente Orthodox joodse autoriteiten met betrekking tot het niet opstarten en stopzetten van behandeling. Deze visies worden kort geconfronteerd met Conservative en Reform perspectieven op het topic. Dit hoofdstuk focust zich op de joodse nadruk op levensbehoud, en toont (opnieuw) dat joodse visies met betrekking tot de aanvaardbaarheid van het afzien van/stopzetten van behandeling sterk gediversifieerd zijn. Uiteenlopende opinies vinden we terug in alle joodse stromingen.

De hoofdstukken die focusten op joodse perspectieven op orgaandonatie, euthanasie en niet opstarten/stopzetten van behandeling hadden tot doel een eerste noodzakelijke kennismaking met het specifieke karakter van het joods ethisch redeneren te bewerkstelligen. De hoofdstukken geven blijk van de eigenheid van joodse medische ethiek: een casuïstisch karakter en een 'heterogene specificiteit'. Rabbijnen die zich inlaten met hedendaagse ethische vragen in de gezondheidszorg, doen een beroep op een gemeenschappelijk arsenaal van waarden, principes, teksten, die niet noodzakelijk door allen op elk moment gedeeld en op een zelfde manier geïnterpreteerd of gebruikt worden.

In de volgende drie hoofdstukken spitst het proefschrift zich toe op het actuele ethos van een specifieke groep joden die in Antwerpen (België) leven. Van juni 2008 tot januari 2009 werden 23 face-to-face interviews afgenomen met oudere ($\geq$ 60 jaar) chassidische, niet-chassidische Orthodoxe en geseculariseerde Orthodox joodse vrouwen in Antwerpen. Gezien het vrouwelijke geslacht van de onderzoeker en de strikte scheiding tussen mannen en vrouwen in het traditionele jodendom, werden enkel vrouwen ingesloten in de studie. In het proefschrift belichten we achtereenvolgens de visies van onze onderzoekspopulatie op a) ziekte en geneeskunde, b) actieve levensbeëindiging, en c) niet-behandelbeslissingen. In deze hoofdstukken ontwikkelen we enkele tentatieve concepten met betrekking tot de link tussen joodse geloofsovertuigingen en ethische attitudes. Bij Orthodox joodse respondenten vonden we voornamelijk een afwijzing van elke handeling die werd geïnterpreteerd als actieve levensbeëindiging, omwille van hun sterke nadruk op

de heiligheid van het menselijk leven. Geseculariseerde Orthodox joodse respondenten waren meer geneigd actieve levensbeëindiging te aanvaarden. Bij hen vonden we meer nadruk op kwaliteit van menselijk leven en op menselijke autonomie.

Verder toonde onze empirische studie aan dat de link die we in onze sample vonden tussen religie en ethiek heel complex is. Sommige religieuze vrouwen keurden euthanasie goed, ondanks hun geloof in God. Wij ontdekten dat niet zozeer het joods zijn, maar wel *wat de respondenten geloofden* en *het beeld dat zij hadden van God*, een belangrijke impact had op hun morele attitudes. In onze empirische resultaten ontdekten we, ten eerste, dat respondenten die niet geloofden in God of in een transcendente werkelijkheid, meer geneigd waren het absolute zelfbeschikkingsrecht van een persoon met betrekking tot leven en dood te benadrukken. Leven, dood, ziekte en gezondheid werden niet geassocieerd met God of met een transcendente werkelijkheid, maar werden op een zuiver profaan niveau benaderd en geïnterpreteerd als zuiver toeval. Deze respondenten toonden zich heel tolerant ten opzichte van actieve levensbeëindiging en niet-behandelbeslissingen. Ten tweede, respondenten die geloofden in een almachtige, alwetende God waren eerder geneigd om het menselijk lot in Gods handen te leggen. Zij geloofden dat God de wereld geschapen heeft, dat Hij het leven en de dood van mensen regeert. Zij interpreteerden leven, gezondheid, ziekte en dood op een transcendent niveau, en waren aldus meer geneigd om menselijke interventie in de sfeer van leven en dood af te keuren. Aldus namen deze respondenten een heel negatieve houding aan ten opzichte van elke handeling die zij als actieve levensbeëindiging beschouwden: euthanasie, hulp bij zelfdoding, en vaak ook niet-behandelbeslissingen. Ten derde, respondenten (Orthodox of geseculariseerd Orthodox) die geloofden in God, maar die weigerden te geloven in Gods almacht met betrekking tot leven, dood, ziekte en gezondheid, waren meer geneigd om nadruk te leggen op het zelfbeschikkingsrecht van mensen aan het einde van het leven. Zij redeneerden dat God niet wil dat mensen lijden, wat ruimte laat voor het beëindigen van leven in een situatie van ondraaglijk lijden.

In vergelijking met de reeds eeuwenlange joodse aanwezigheid in het land, is de opkomst van de islam in België vrij recent. Sinds de start van moslimmigratie naar België in de late jaren 1950, blijft de moslimpopulatie aangroeien. Hiermee rekening houdend, en gezien het feit dat eerste generatie migranten van Marokkaanse en Turkse origine vandaag oud worden, en aldus groeiende medische noden hebben, beschouwden we het belangrijk om islamitische visies op ethische dilemma's waarmee men aan het levenseinde kan geconfronteerd worden, te onderzoeken. Specifiek focust dit tweede deel van het proefschrift op een presentatie en discussie van de onderzoeksdata verworven bij onze verkennende, kwalitatief empirische studie in de Turkse en Marokkaanse moslimgemeenschappen in Antwerpen (België). Gezien de onderzoeksexpertise van het

Interdisciplinair Centrum Religiestudie en Interlevensbeschouwelijke Dialoog (KU Leuven) - normatieve islamitische visies op ethische dilemma's in zorg aan het levenseinde werden in het verleden reeds uitgebreid onderzocht en neergeschreven - vonden we het niet noodzakelijk een apart hoofdstuk te wijden aan een overzicht van de eigenheid van islamitische medische ethiek in het algemeen. Daarom focust het tweede deel op het reconstrueren van de denkwereld van een specifieke groep moslims die in Antwerpen (België) leven met betrekking tot religie, geneeskunde, ziekte en specifieke medische beslissingen aan het levenseinde. Van juni 2009 tot januari 2011 werden interviews afgenomen met 30 oudere (≥ 55 jaar) eerste generatie moslim vrouwen van Marokkaanse (15) en Turkse (15) origine. De onderzoekster werd daarbij geholpen door twee ervaren tolken, die vloelend Turks, Marokkaans en Berbers spraken. Rekening houdend met de segregatie van seksen in islam, en met het *vrouwelijke* geslacht van de onderzoekster, werden enkel moslim*vrouwen* gerekruteerd om aan het onderzoek deel te nemen. In drie opeenvolgende hoofdstukken in het tweede deel van het proefschrift, belichten we de visies van de respondenten op a) geneeskunde, ziekte en lijden, b) actieve levensbeëindiging, en c) niet-behandelbeslissingen. Telkens wordt in de hoofdstukken ook aandacht besteed aan normatieve islamitische standpunten.

Samenvattend kunnen we stellen dat de ethische attitudes van onze respondenten bijna homogeen waren. Dit is gerelateerd aan de homogeniteit van hun religieuze overtuigingen. De overgrote meerderheid van onze respondenten geloofde in een almachtige en alwetende God. Ze geloofden dat God oordeelt over de manier waarop mensen leven, en dat dit repercussies heeft in het hiernamaals. De respondenten benadrukten hun geloof in Gods soevereiniteit met betrekking tot leven en dood. Aldus spraken ze zich negatief uit over elke medische handeling die volgens hen zou kunnen bijdragen aan de dood van een patiënt: euthanasie, hulp bij zelfdoding, actieve levensbeëindiging zonder verzoek, en meestal ook niet-behandelbeslissingen. Kleine verschillen werden gevonden tussen Turkse en Marokkaanse respondenten.

Tezelfdertijd merkten we bij sommige moslima's in onze studie ook openheid voor euthanasie. Eén Turkse en één Marokkaanse respondente, beiden diep religieus, spraken zich positief uit over actieve levensbeëindiging. Zij minimaliseerden Gods soevereinitelt met betrekking tot de dood, en lieten ruimte voor menselijk zelfbeschikkingsrecht aan het einde van het leven. Volgens hen beschermt God de mens, en beslist Hij niet over ziekte en lijden. Op die manier suggereert onze studie dat vroom moslim zijn niet automatisch een afkeuring van actieve levensbeëindiging impliceert. We merkten ook op dat persoonlijke confrontatie met ziekte een invloedrijke factor kan zijn. We ontdekten dat specifieke religieuze overtuigingen, bijvoorbeeld over karakteristieken die aan God worden toegedicht, een belangrijke invloed kunnen uitoefenen op visies met betrekking tot

specifieke ethische dilemma's die kunnen opduiken in de zorg aan het levenseinde. De overgrote meerderheid van onze islamitische respondenten drukten een absolute afkeuring uit ten opzichte van elke handeling die ze beschouwden als actieve levensbeëindiging. We concludeerden dat deze attitude sterk gerelateerd is aan hun Godsbeeld: almachtig, alwetend en oordelend.

De epiloog van dit proefschrift wil enkele comparatieve perspectieven aanbieden met betrekking tot de denkwereld van onze joodse en islamitische respondenten met betrekking tot medische beslissingen aan het levenseinde. Dit afsluitend hoofdstuk biedt enkele tentatieve inzichten in de manier waarop joodse en islamitische geloofsovertuigingen en praktijken de wijze waarop specifieke morele dilemma's aan het levenseinde worden benaderd, zouden kunnen beïnvloeden. Terwijl we zeer voorzichtige conclusies formuleren, houden we ook rekening met het feit dat - wanneer we visies van onze joodse en islamitische respondenten vergelijken - bepaalde variabelen, zoals socio-economisch niveau en scholingsgraad, grondig verschilden. Deze epiloog houdt rekening met het multidimensioneel karakter van religie, en verkent welke facetten van religie het meest invloedrijk bleken in de link tussen religie en ethiek die we ontdekten in onze empirische studies. Op die manier wordt in deze epiloog de invloed van de religiositeit van onze respondenten op de manier waarop zij omgaan met ethische dilemma's geadresseerd. Samenvattend kunnen we stellen dat onze studieresultaten aangeven dat verschillende dimensies van religiositeit een invloed uitoefenen. De belangrijke impact van de ideologische dimensie van religiositeit (Godsbeeld en overtuigingen over God en de transcendente werkelijkheid) is het meest markant. Onafhankelijk van religieuze affiliatie, vonden we dat respondenten die geloofden dat God almachtig is, dat God mensen op de proef stelt, en dat God de daden van de mens evalueert na diens leven op aarde, eerder noopten naar een negatieve attitude ten aanzien van elke handeling die zij beschouwden als actieve levensbeëindiging. Deze respondenten verwierpen niet enkel euthanasie, actieve levensbeëindiging zonder verzoek en hulp bij zelfdoding, maar ook stopzetten (en vaak ook niet opstarten) van behandeling, aangezien ze (ook) dit beschouwden als bijdragen aan de dood van een patiënt. Bovendien toont de epiloog ook dat andere factoren, zoals persoonlijke confrontatie met (ernstige) ziekte, een belangrijke impact kunnen hebben op de wijze waarop ethische dilemma's in de zorg aan het levenseinde worden benaderd, en dat deze visies kunnen genereren die verschillend zijn van wat in de regel als de normatieve Orthodox joodse of islamitische visie wordt beschouwd.

Stellingen

1. De meerderheid van de Orthodox joodse respondenten wijst elke handeling die wordt geïnterpreteerd als actieve levensbeëindiging af, omwille van een sterke nadruk op de

heiligheid van het menselijk leven, terwijl geseculariseerde Orthodox joodse respondenten meer geneigd zijn actieve levensbeëindiging te aanvaarden, omdat zij belang hechten aan zelfbeschikkingsrecht en levenskwaliteit.

2. Oudere, eerste generatie moslima's in Antwerpen (België) uiten bijna homogene religieuze en ethische visies: elke medische handeling die zou kunnen bijdragen aan de dood van een patiënt wordt afgewezen, aangezien dit de soevereiniteit van God in het domein van leven en dood zou tegenspreken.

3. Joodse en islamitische vrouwen in Antwerpen (België) die geloven in een almachtige, levengevende, oordelende God, zijn minder geneigd om medische beslissingen waaraan zij een levensverkortend effect toedichten, goed te keuren.

4. Wanneer men leven, dood en ziekte interpreteert op een zuiver profaan niveau, is men meer geneigd om het zelfbeschikkingsrecht van een persoon met betrekking tot leven en dood te benadrukken, en lijkt men toleranter ten opzichte van actieve levensbeëindiging en niet-behandelbeslissingen.

5. Persoonlijke confrontatie met ziekte kan een impact hebben op de manier waarop ethische dilemma's in zorg aan het levenseinde, bijvoorbeeld actieve levensbeëindiging, worden benaderd; het kan visies genereren die verschillend zijn van wat in de regel als de normatieve Orthodox joodse of islamitische visie wordt beschouwd.

6. Islamitisch en joods ethisch redeneren worden beiden gekarakteriseerd door hun casus-gerichte aard, die flexibiliteit en diversiteit in beide tradities toelaat.

7. Onze bevinding dat gelijkaardige religieuze overtuigingen een sterke invloed hebben op de attitudes van joodse en islamitische respondenten met betrekking tot hete ethische hangijzers in de zorg aan het levenseinde, biedt interessante opportuniteiten voor interreligieuze dialoog.

8. Gezien de toenemende multiculturele en multireligieuze diversiteit in onze hedendaagse gezondheidszorg, is het een enorme, maar niet te verwaarlozen uitdaging om rekening te houden met de (culturele) achtergrond van patiënten en hun religieuze overtuigingen die een belangrijke inlvoed kunnen uitoefenen in het medisch beslissingsproces.

9. De toenemende pluraliteit van religies en culturen in hedendaagse westerse samenlevingen spoort zorgverleners aan om te erkennen dat medische beslissingen niet waardeneutraal zijn, en aldus aandacht te besteden aan het ontwikkelen van een contextuele gevoeligheid, het verhelderen van verschillen tussen het eigen waardesysteem en dat van patienten, en het ontwikkelen van effectieve communicatie.

10. Heterogeniteit is karakteristiek voor zowel jodendom als islam; aldus is het niet gepast om joodse en islamitische patiënten op een simplistische, stereotiepe en ongenuanceerde manier te benaderen.

BIOGRAPHY

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Recent publications are:

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